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ALZHEIMER'S DISEASE AND RELATED DISORDERS

HEARING

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

ON

OVERSIGHT INTO CORRECTING CERTAIN INADEQUACIES THAT EXIST IN THE CARE OF VICTIMS OF ALZHEIMER'S DISEASE AND RELATED DISORDERS

NOVEMBER 9, 1984

CLEVELAND HEIGHTS, OH

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ALZHEIMER'S DISEASE AND RELATED DISORDERS

FRIDAY, NOVEMBER 9, 1984

U.S. SENATE,
SUBCOMMITTEE ON AGING,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Cleveland Heights, OH.

The subcommittee met, at 10:08 a.m., at Judson Retirement Community Auditorium, Cleveland Heights, OH, Senator Howard M. Metzenbaum presiding.

Present: Senator Metzenbaum.

Also present: Representative Mary Rose Oakar.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator **METZENBAUM**. The hearing will come to order.

I want to welcome everyone this morning to the Senate Subcommittee on Aging. As you all know, we are here to listen to testimony on a topic that threatens to be the most serious health problem that faces us in the next century, Alzheimer's disease.

With the testimony that we will hear today, I am hopeful that we can all leave here with a better understanding of the disorder itself and the toll it takes on so many people's lives. I also hope that we will more clearly see the cracks that currently exist in our health care system in this regard and, more importantly, discover some possible means or method for sealing those cracks.

Finally, I have asked some of the best researchers in this field to present to us a report on the latest developments in the struggle to find treatment and cure for this cruel killer.

We have some outstanding experts to speak here today and I might say parenthetically that I am particularly pleased that we have as part of our audience today two distinguished physicians from the Cleveland Clinic and I do appreciate their being in attendance as well.

Congresswoman Oakar, I am told, will be joining us shortly and she has certainly evidence continued concern in this subject.

For the past few years, the Congress of the United States has designated the month of November as Alzheimer's Disease Awareness Month. We do this every year in the hope that the collective conscience of the country can be raised on the issues surrounding Alzheimer's, but frankly that is not necessary. It is not necessary for us to have an Alzheimer's Disease Month because Alzheimer's is striking in so many areas and so many people and it has become a common byword today. And in this audience today there are many close personal friends of mine whose families have been afflicted by the onslaught of Alzheimer's disease. So we do not need a month to make us aware of it. We cannot help but be aware of it.

Alzheimer's disease and the devastation that follows it is beyond compare. I think that 20 years ago if you had mentioned Alzheimer's, people would not have known what you were talking about. And 10 years ago a few people would have known what you were talking about, but in recent years it is too well known.

The numbers involved are staggering. The numbers actually do not tell the whole story. We have to confront the statistics, the millions of victims, the thousands of deaths, the billions of dollars, but alone they simply cannot demonstrate the scope of this tragedy, because it is not alone a matter of statistics or dollars, it is the pain that people feel as they helplessly watch a loved one disintegrate.

One person in this audience, an old friend of mine, told me that he has lived with it, the condition of his wife, for the past 13 years. There is an anguish and a frustration that does not show up on any chart. That is the anguish of a family that crumbles emotionally as well as financially.

We are now only beginning to understand the nightmare that is Alzheimer's disease, and it is fair to say we are making some progress, but not enough.

Last fall, I introduced an amendment in the Senate that would create five specialized Alzheimer's research centers around the country. Now, it was an interesting development that occurred in the committee when I offered that amendment, and I want to share it with you.

When I offered it, one member of the committee said: "Does not this committee have a policy against any individual raising of funds for any particular illness," because realistically speaking it is very difficult for anybody to object to raising research funds for heart, or for cancer, or diabetes, or any one of the many other illnesses with which we are all familiar.

I remember the chairman responding: "That is the policy of the committee but I know that the Senator from Ohio sits with enough proxies in his pocket that he is going to prevail," and I sat with the proxies because nobody could say no to me because they all knew of its impact. As a matter of fact, there is one Member of the Senate whose dad has Alzheimer's.

This year, in addition to the funds that we made available last year for five research centers, we have made funds available for five more centers. Last spring, I offered an amendment to the Older Americans Act which provided $5 million for demonstration projects and grants for students who will specialize in the care of Alzheimer's patients, and we are prodding and have been effective in getting an amendment through indicating to the Veterans' Administration a sense of responsibility on their part to come up with some answers as to how that agency should deal with the problem of Alzheimer's because, generally speaking, the Veterans' Administration only treats patients who have service-connected illnesses, and the issue of whether Alzheimer's is service-connected is not often claimed that it is, at least I have seen no evidence to that effect. But notwithstanding that, I for one feel that the VA has some responsibility in the arena.

We made some first steps. Establishing research centers does not create a cure, does not provide the answers. I am sure we will hear more today that so much more is needed, and that is exactly why we are here. I am not going to kid anybody. This hearing is not going to solve the problem. This hearing is an indication of continued concern on the part of the U.S. Congress with the problem and an indication that we intend to act affirmatively.

In that connection, I have a letter from the chairman of the committee, the Subcommittee on Aging, Senator Charles Grassley:

> Being unable to attend and chair the field hearings on Alzheimer's, I congratulate and thank Senator Metzenbaum for preparing and chairing the Subcommittee on Aging's third 1984 inquiry into the research, personal, and societal needs created by this insidious disease.
>
> The previous hearings held in Washington in May and October have provided a rich resource of information which the Congress has and will continue to use in evaluating the Nation's legislative and funding needs in the battle to diagnose and cure Alzheimer's. Thanks to Senator Metzenbaum, this hearing will add some more data to this aresenal.

I might say that the battle against Alzheimer's is not a partisan battle. It is a bipartisan battle and all of us in the Congress feel very strongly about it.

I am happy to, in a moment, go to Congresswoman Oakar. We are happy to have you with us this morning.

Hopefully we can explore today the inadequacies that now exist in the care of an Alzheimer's victim and begin to work on solutions. What we have here is literally an epidemic on the horizon, but it is an epidemic that we can anticipate and avoid, and therefore we are going to have to accelerate and increase research toward a cure, while at the same time hopefully making the lives of today's victims and their families more livable. I sincerely believe that today's hearing can act as a catalyst toward that goal.

Now, before we start I feel that I must mention that one witness who was scheduled to testify today could not be with us. Kate Koenig lost her husband, Joe, to Alzheimer's disease on Tuesday of this week. Joe Koenig was a former marine who twice received the Purple Heart in World War II. He was 66 years old and had suffered from Alzheimer's disease for over 8 years. Our heartfelt condolences go out to Kate and her family today.

Congresswoman Oakar, I am very happy to welcome you, and if you would like to make and opening statement, we are certainly very pleased to have you do so.

STATEMENT OF HON. MARY ROSE OAKAR, A MEMBER OF THE HOUSE OF REPRESENTATIVES FROM THE 20TH CONGRESSIONAL DISTRICT OF THE STATE OF OHIO

Ms. **Oakar**. Thank you, Senator Metzenbaum. I think all of us in our State and our Greater Cleveland area are very proud of the leadership that you have taken on this very important issue and very sad issue. We know that more than 1 million people over age 65 are afflicted by Alzheimer's. We know younger people and middle-aged people are also afflicted. We know that 3 to 4 million people will suffer from Alzheimer's disease by the year 2000. And we know one of the most frequent reasons for institutionalization of our elderly is due to this terrible disease, and we know as a matter of fact that half of the nursing home residents are afflicted by Alzheimer's disease.

Although we are still working on a definitive cause, there has been some progress and I think, thanks to the money, Senator, that you are responsible for getting in terms of research and development related to the Labor and Education appropriations, we also targeted some money in the Older Americans Act, so that we can find an avenue by which to treat this terrible disease.

Senator, I am very happy to be here with you and look forward to the witnesses and hopefully with hearings like this we can find some solutions. And I think unless we in Congress push for the necessary research, we are just not going to give our great scientists in this country the opportunity and the leisure to be able to work on this, on finding a cure—that is what we want, a cure—for Alzheimer's disease.

Thank you very much, Senator Metzenbaum.

Senator **Metzenbaum**. Thank you very much. Thank you for being with us.

Our first panel consists of Hap Richards, Evelyn Bonder, and Ernestine Lee. Would they come to the front table, please.

As we set up this hearing, I want to publicly thank Joel Johnson, seated to my right, who has done a yeoman's job in assembling the witnesses, bringing some in from out of the city as well as those from the local community. I am grateful to you, Joel, for what you have done.

We have asked each of the witnesses to confine themselves to 5 minutes only because we have so many witnesses today, so that all will understand. Please be seated.

STATEMENTS OF HAP RICHARDS, OLMSTED FALLS, OH; EVELYN BONDER, CLEVELAND HEIGHTS, OH; AND ERNESTINE LEE; SHAKER HEIGHTS, OH

Mr. **Richards**. Senator Metzenbaum and distinguished guests, I am Hap Richards, as listed. My full name is Hadley Richards, and my address is 24744 Water Street, Olmsted Falls. I am 63. I am a care giver.

I am a graduate of Case Institute of Technology here in town and have worked most of my life for NASA, both at Langley and at Lewis. I retired from NASA in 1971 and found that distasteful and so I began looking for other things to do and in 1974, after I had been working a short time as a sales engineer, I noticed difficulty with my wife and she was taken to Cleveland Clinic by us and after a week's evaluation they decided that she had Alzheimer's disease.

At that time we were told that there was nothing that could be done, there was no treatment. The only thing we could do was to go home, and one other statement which was erroneous, in that my hospitalization would take care of the problem. So we did that and a year later we returned to the clinic for additional tests, mostly psychological, to confirm as best they could whether or not she had the disease and the conclusion was that she did.

Her deterioration in the first 2 years was very slow and she continued to conduct normal activities at home. I left her at home. I was working every day and she was alone at home for about 2 years. At the end of that time, fortunately while I was at home, she had a seizure, which occasionally happens with patients of Alzheimer's. We were not told that that could happen. It was unexpected. We put her in the hospital for 3 days. At the end of 3 days she had recovered sufficiently to go home, but at that time we knew that we would not be able to leave her alone at home any more because this could happen again, even though she had been put on Dilantin, which is the common medicine for combating people with that difficulty. It happens in epilepsy. The seizure is very similar to an epileptic seizure.

So at that time I found very fortunately a lady who would come and stay with her during the day while I worked and she got along very well. They took trips, they went out for lunches, they behaved quite well. She was slowly losing the ability to appreciate television. She made some effort at reading during that time. She lost the ability to write with a pencil or pen. She could still type I think for a while.

At the end of about 2 more years, again fortunately while I was at home—it was early in the morning—she had another seizure and by that time I had been alerted and knew roughly what to do and took care of her and did not hospitalize her but she had complained about a back problem—it was hurting her. I could not believe it hurt her because she had fallen—when she had the seizure she fell onto the bed and I could not believe she had been injured. So finally our attending physician at that time, who is a local internist, come to the house and examined her and said she had damaged her back in some way and we had better put put her back in the hospital.

So we did that and she was in the hospital for roughly 2 weeks, where she had therapy and was doing fairly well but at that point the doctor convinced me that she should go into a nursing home because if she did not I probably would be a patient in the same hospital because I was wearing myself out day and night. I worked in the daytime and frequently—I am leaving out many of the unpleasant details of the deterioration. There was hysteria, there was the—she had problems with—I can't think of the proper adjective at the moment, but it has to do with seeing unexplained things, let us say, and she kept me awake a good bit at night.

My daughters were away at the time when she was diagnosed. They all lived in other places and they became, of course, very concerned and they were able to transfer their jobs and/or their places of abode and they all returned to this area and they came and stayed with me each, one after another, for periods of time during this time when my wife was at home, and that helped to some extent.

Finally, to get back to my train of thought, we did put her in the nursing home and that was in about December 1979 and she has been a patient in a nursing home ever since and has not left the nursing home. When she went in, she was able to walk. She did not communicate very well. There were times when she could and other times she could not. In that 5-year period she has now become completely bedridden, has lost the ability to take care of any of her needs. She has lost an extreme amount of weight. She is down to about 85 pounds now. She originally was around 135, and she exists in that state.

Senator METZENBAUM. What does it cost you to keep her in the nursing home?

Mr. RICHARDS. The nursing home expenses run between $1,800 and $2,000 a month and have been about at that level. The costs have been increasing ever since we went in. We pay now a rate which is equal to what had been the premium rate for individual rooms and individual patients 5 years ago at this point. We are in a three bedroom and it costs as much as that did at that time 5 years ago because of increased costs.

Senator METZENBAUM. How can you keep your head above water and continue?

Mr. RICHARDS. Well, the combination of the job that I now have, which is a sales engineer—I am a manufacturer's representative—in combination of that and the retirement that I get from my years as a Government employee have so far kept my head above water. I will say that if anything happens to me, then she may eventually go on welfare because my children are not financially able to support her at this point anyway. All three of my daughters are married and are struggling to maintain their own living standards.

Senator METZENBAUM. What would you say has been the most difficult part of the entire experience for you?

Mr. RICHARDS. I would say watching the deterioration of a beautiful, intelligent woman. It has reached the point now where it is less of a burden, but that period when she was rapidly deteriorating was a very difficult time.

Senator METZENBAUM. Thank you very much, Mr. Richards.

Ms. OAKAR. Senator, I just wanted to ask—Mr. Richards' testimony really shows the need for support services. We are looking for a cure for Alzheimer's, but in the meantime what do we do about giving him some respite for the day-to-day care that is necessary? Obviously, if you could have, you would prefer not to have her institutionalized, if you had the kind of services perhaps her situation has deteriorated so you have no other recourse, but families really have a difficult time taking care, no matter how much love they have.

Senator METZENBAUM. Of course, how many families could afford $24,000 a year?

Ms. OAKAR. That is right.

Senator METZENBAUM. Fortunately, you are working and have a pension, but that exceeds the income of many families in America.

Mr. RICHARDS. Yes.

Ms. OAKAR. That's right.

Mr. RICHARDS. I have heard since I have been associated with the local chapter on Alzheimer's disease here, some very bad cases. I know of one man, for instance, who was taking care of his wife, he had to sell his house. He was using the money he got from his house and he was terribly worried because it was getting to be a race whether she was going to die before he ran out of funds or not, and he had moved in with his son, for a place to live. His wife was in a nursing home and he was, let us say, fortunate that his wife died and left him a few small dollars from the sale of his house at the end of that period.

Ms. **Oakar**. We had one of the children of Rita Hayworth, testify the very fine actress who was afflicted by this disease, and cannot even maintain the cost so obviously the average American has difficulties.

Mr. **Richards**. I consider myself fortunate, if you can look at it this way, as compared to many of the people I have associated with here in Cleveland.

Senator **Metzenbaum**. I know, because I know some of the person's stories.

Mr. **Richards**. Yes.

Senator **Metzenbaum**. Evelyn, why do not we hear from you at this point, Evelyn Bonder. Evelyn Bonder is an old friend of mine. We went to junior high or high school, I am not sure which one.

Ms. **Bonder**. High school.

Senator **Metzenbaum**. High school, all right.

Ms. **Bonder**. My name is Evelyn Bonder, and I am a widow of an Alzheimer's victim. I am on the board, as Hap, of the Alzheimer's Disease and Related Disorders Association here locally, and I am currently employed part time by CIVAC, which is the Community Information Volunteer Action Center.

My husband was a very competent man. He was professionally a social work administrator, the administrator-director of a major social agency here in Cleveland. He was also the director of a children's camp. And in addition to the normal demands of administration, he was called upon to oversee the building of a new camp and to help with the building of a new facility for his agency.

He was a man of total integrity and a man who was influential in the development of younger social workers who were in high positions in communities and agencies——

Senator **Metzenbaum**. I will vouch for everything you say, because I knew him well. I was on the board of the agency that he was the director of and he was a fantastically able, solid citizen in the community.

Ms. **Bonder**. But Alzheimer's disease is no respector of integrity or competence or ability, and in his final months my husband was not able to read, write, think, remember, or speak coherently. He did not know his friends or his children and he did not know his wife, and he spoke babbling phrases repetitively, he made repetitive motions compulsively. I think he weighed at that time about 85 pounds, too.

The earliest beginnings are masked by depression which appear to have some relation to the fact that he had cataracts and we discovered he had one in one eye and then the other, so the depression did not seem abnormal at the time. He was in his sixties when the symptoms began. He began to be unable to write checks, to share in the chores. He exhibited extreme panic in crowds.

In the beginning, when he still could understand some of what was happening to him, the sheer panic that he was experiencing was painful to witness. I had a job at the time, too. It was a responsible and fairly well paying job at Tri-C, but even more, it was a fascinating job. It had given me the opportunity to help women enter careers, advance in their careers, to help women who had become displaced homemakers, and to participate in the beginnings of the feminist movement. So it was exciting and my husband had been proud and supportive of my activities but now he needed help.

The diagnosis came in the fall of 1980, and at the time I could not have found a homemaker who could have managed the strange, unpredictable behavior. And even now I find that there is not a whole lot of chance of finding people who can help with that. So there was no alternative for me at the time but to resign my job, and I did that in June 1981.

But in retrospect I can see that with all of the pain that we were suffering, I was more fortunate that many because I had managed to put in enough full-time years to have earned a modest retirement pension, it was almost 25 percent of my final salary and yet it was a major setback because retirement pensions I learned build far more rapidly in the final years when one's salary is at the highest point.

However, we owned our home and my husband had also a modest pension about equal to mine, and I hoped we could make it. I was becoming aware of the financial burdens that so many families were bearing as a result of this. We were fortunate, too, because we had children who cared and who were supportive, because most of our relatives and friends were also and they did not desert us.

For many, Alzheimers disease means friends and relatives do kind of drift away, I think mostly because they simply do not know how to help. And all too often one family care giver is left to face the full burden of it, with what has been called the 36-hour day, and I think we can all vouch for that.

I was fortunate because my job had taught me something about community resources, and my children and my friends taught me even more. For many, there may not be that kind of knowledge, and for most anyhow there are insufficient and inadequate resources.

My children urged me to seek help through the ADRDA which fortunately had just been started then by Arlene Ellis and a few other care givers and Dr. Joseph Foley. With ADRDA, I found support and information and advice and friends who had been through it and understand, a sympathetic ear when I needed one. It was kind of my own personal help line, and I was fortunate because through ADRDA, it was Rachel Billington, in fact, I learned about an adult day-care program here at Judson Park 3 days a week. But there are only a few such programs, not enough to meet the needs, not enough with flexible hours, not enough full time for care givers who must continue working.

I have to admit that the first ADRDA meetings I attended were difficult, distressing, and as I learned more about the progresive and the irreversible nature of the disease and began to realize that my hope for remission or for stabilization was just unrealistic, and I learned about the enormous financial burdens and the legal problems as well.

Then came the day all too soon, just a few brief months when my husband could no longer tolerate a day-care program and then I was not so fortunate. The dangers at home continued to increase. My husband became highly agitated and then came the paranoia, running up and down the stairs from the second floor to the basement continually, day or night, to catch the strangers and the enemies ready to take over our home, and the very real danger when he inserted a 2-inch nail into an electric outlet, and yet he had been a pretty good handyman. He had done a lot of the carpentry and electrical work, and now there was only frustration and anger when all the familiar things were turning into terrible nightmares for him, even bathing and dressing.

The disease continued to take its toll and the 36-hour day became more than I could manage. Finally, when he became psychotic, my husband was hospitalized at the insistence of children and friends. By then I was close to exhaustion and welcomed whatever intervention was possible. For a month, the psychiatrist and the hospital staff tried to regulate medication and manage his behavior. Today, with DRG's, that would not be possible either.

Then came the search for a nursing home. Medicare does not cover what is described as custodial care, and Medicaid is available only when one's resources are all spent. I suppose the spouse who is still living in the community would then have to depend on welfare. No insurance, public or private, covers the cost of what is defined as custodial nursing home care. It is called unskilled care, but you cannot find people with the skill to deal with it. For that care, $2,000 a month is not unusual, and that is $24,000 a year. That was more than our combined pensions and that would not include medication or physician fees, and so the nightmare for both of us continued to worsen.

My husband was a World War II veteran who had never received any veterans' benefits other than GI term insurance for which he paid, of course. We turned to the Veterans' Administration for help. I think you remember that, Senator Metzenbaum.

Senator **Metzenbaum**. I do very well.

Ms. **Bonder**. The VA could not admit my husband to their nursing home because his was not a service-related illness and he had been admitted to a private hospital and not their's. Regulations at the time seemed to be tightening and we were not eligible.

We finally found a nursing home but my husband did not do well there, and within 5 months, to my dismay, the administrator told me that they could no longer manage him and I would have to look for another nursing home. We were still searching frantically and desperately for one when very suddenly and very unexpectedly, 6 months after he was admitted, my husband died.

It was April 13, 1983, and the death certificate noted that the cause of death was cardiorespiratory arrest with secondary causes being Alzheimer's disease and pneumonia. After the initial shock, we recognized that his death was a release for him and a blessing. We had already mourned for weeks and months and years, and we would continue to mourn, probably daily. But we would also continue to join in the task of arousing awareness of this terrible disease and trying to provide those adequate community resources and support and encouraging the research that would free our children and our grandchildren from suffering the same experience.

Senator Metzenbaum, may I take just a moment to tell you about what I think might be needed?

Senator **Metzenbaum**. Please do.

Ms. **Bonder**. I think I can speak for many others when I say I do appreciate so very deeply the efforts that you are making on behalf of Alzheimer's victims and their families. We know that you have been at the forefront of the effort and we hope that the bills you are introducing are going to set in motion the programs that will alleviate the problems of the care givers and one day eradicate that disease.

We are hoping that those community-based services that you have suggested will include a full range of support services, including respite care and day care and help lines and in-home help services and nursing home services by trained aides, and we would be privileged to work with you on that. And we hope that insurance coverage, Medicare and private, could be designed to aid Alzheimer families, or that custodial care could be redefined to permit Medicare coverage, and we will work with you toward that end.

We hope that there will be a full-scale effort to expand the research on the brain. It holds promise, it seems to me, not only for Alzheimer's disease but for many other related diseases and for mental disorders. We hope that ADRDA can have the privilege of working with you and with Federal, State, and local governments and agencies to bring hope to the 2½ million victims and their families until that day when there will no longer be any victims.

Thank you.

Senator **Metzenbaum**. Thank you very much, Evelyn. I am not going to ask you any questions, as time is running a little short. I am getting a little worried because our last three witnesses today are people who talk to the issue of a cure and what lies ahead in the medical field and I do not want to cut them short and I do not want to cut anybody short, but the 5 minutes has run to 10 or 15 minutes for each, but I just did not have the heart to cut you short. If the future witnesses could try to make their statements in 5 minutes, it would be helpful only because we have so many witnesses today.

Our next witness is Ernestine Lee.

Ms. **Lee**. Good morning, Senator Metzenbaum and Congresswoman Oakar. My name is Ernestine Lee and I am a care giver for my mother who is 90 years old. I have been taking care of her since about 1969, when I first noticed that she was having difficulty with memory less.

I finished Kent State University with the hope and expectation of teaching school and helping financially with the rearing of my children. However, I had to give up that ambition because my mother's condition I felt took precedence over some of the ambitions that I had in regards to perhaps making a better financial life for us.

She was a very, very kind, giving mother and one who had made great sacrifices for her family and rearing her children. As has been mentioned, it was very devastating to me to see the deterioration under which she was laboring. Her personality changed drastically, as is generally done with Alzheimer's victims, and it worked a great hardship on our family as well as many friends who were not able to understand her condition.

I will not go into the details of personality changes and all of that, as many people are familiar with that. I just would like to say some of the problems that I have faced in trying to get assistance or relief for myself—I would say about 1979 I had become very, very tired and nervous and worn from the care for 10 years of her, and I attempted to find some source of relief to assist me. I was unable to to do so. I tried every agency that was referred to me.

Eventually I brought her here to the center for 3-day relief and Bobby Miller who is on staff here suggested to me that I would call someone at the Chronic Illness Center. On that particular day I was very distraught because my mother had given me a very, very hard time and the center was not able to offer me anything but they did refer me to COMPAS which is an agency that helps with home-bound patients. Through them I was able to get some relief some mornings a week because she had reached a point where I was no longer able to bathe her or do anything for her.

She is still very combative. Even this morning we had a very difficult time bathing and dressing her. Her disease has been very, very slow progressing and I think a lot of help has come from family support, giving her the care and the love and the attention that has been helpful that she would not, I am sure, be given in an institution, and that has been one of our prime objectives, has been to try to keep her at home as long as we possibly can, so that she can be close to her family, and I think that has sort of helped, too.

Senator **Metzenbaum**. Ms. Lee, let me ask you a question. You and your husband are both retired. He is a retired postman and you are a retired school teacher?

Ms. **Lee**. Yes.

Senator **Metzenbaum**. Now, it sounds to me that you have both been wonderful as a daughter and as a son-in-law. My question is, What has this done to your retirment years, what impact has this made on your life, your ability to go out at night, your ability to go out in the afternoon to go to see somebody? Has this become an all-encompassing kind of responsibility, or how have you handled that?

Ms. **Lee**. Yes; it has. My husband has been marvelous. He has been very supportive and he has been very patient and understanding with her condition and with me. We have been very limited because our social life has been almost nil. I dare not go even to the store without having someone watch her. We do not go out evenings. We almost do nothing.

We have five children and they are all in various cities, so most of our close relatives are within our age group, and there is just no help that we have in the day or evening with her.

The retirement aspect has been one that we have just not even had a chance to realize. We are unable to do anything together because of her.

Ms. **Oakar**. Senator, I just wanted to say that—and I was remiss in not saying this earlier—that Judson Park is one of the few programs in the country that has any kind of care for this difficulty that is partial care and temporary respite for the family. It is just a phenomenon that we have not addressed adequately.

Senator **Metzenbaum**. Thank you very much, each of you. I am grateful to you and we hope you can remain with us, if you can.

Ms. **Oakar**. I just want to say, Evelyn Bonder gave up a brilliant career at community college. She was a colleague and friend and did so much for so many people, especially women. I will tell you, I think the courage that your witnesses have in coming forward, Senator, is really important.

Senator METZENBAUM. Thank you.

Are you going to remain with us?

Ms. LEE. Yes.

Senator METZENBAUM. I wanted to explore some of those ideas that you mentioned.

Our next three witnesses, our next panel consists of Homer Cotton, Bob Cholfin, and Arlene Ellis.

Homer, we are happy to hear from you first, only because I had your name on the list first and for no other reason. Please proceed.

STATEMENTS OF HOMER COTTON, CHARDON, OH; BOB CHOLFIN, UNIVERSITY HEIGHTS, OH; AND ARLENE ELLIS, BEACHWOOD, OH

Mr. COTTON. My wife has noticeably deterioriated in the last year or so. When I first noticed it was last year or so at work—she was a private secretary—she had very high intelligence. She was on the honor roll and had been a very smart person and I could hardly believe that she was losing her ability in different things. I noticed it at work and the bosses were being impatient with her and it finally made her last year at work a chore.

Finally, when she did retire she could handle herself at home by herself for a few years and I had to continue on working so I could retire. After I retired, it was more or less like just going from one job to another taking care of her.

She slowly lost her ability to read and write and she lost interest in more things as she went along in progressing years.

Being a very sociable person, she always liked people which is more to her advantage. She still likes people even though she cannot quite express herself. She has lost all ability to make coherence. She has lost consistency as well. It takes full time in bathing her, feeding her, and everything.

I get help a couple of days a week in bathing her from the agency. She has her different moments, of course. I am happy that she is still with me.

Senator METZENBAUM. You tell a very touching story, Homer. Let me ask you, have you ever considered a nursing home?

Mr. COTTON. I am working on it. I am working up to it. I know it is inevitable.

Senator METZENBAUM. It is a diffult thing for you to separate.

Mr. COTTON. Yes.

Senator METZENBAUM. Do you have any time for yourself now? Can you ever go on errands, go to a movie, meet some friends?

Mr. COTTON. If I do, I take her, if I can. I try to—I have not been able to get down to a definite way of getting out, no.

Senator METZENBAUM. You are not able to leave her alone at all?

Mr. COTTON. No.

Senator METZENBAUM. What help would you most like to receive that you cannot get now?

Mr. COTTON. Mainly care, empathy care mainly, that I am trying to get as a person. I can handle her with feeling.

Senator **Metzenbaum**. I thank you very much.

Ms. **Oakar**. Homer, your wife is here today?

Mr. **Cotton**. Yes.

Ms. **Oakar**. And this is a member of your family that helps you?

Mr. **Cotton**. They have their cares. Most of them are far from me and they cannot get to help. They are way over on the west side and I am on the east side, 50 miles apart. They appreciate what I am doing for her. They are good kids.

Senator **Metzenbaum**. Our next witness is Bob Cholfin.

I must say that I did not choose the witnesses. Understandably, a Senator asks the staff to set up the witness list and I am absolutely overwhelmed at the number of people who are testifying who are my contemporaries, my friends. The Cholfins I have known for years. Ms. Ellis, I used to play tennis with her husband. Another man out there in the audience is the first employee my company had. Another man out there whose wife is a business associate of—he is a business associate of mine.

The pervasiveness, the fact that it strikes all segments of society is just shattering, just shattering.

Mr. Cholfin.

Mr. **Cholfin**. I want to thank you, Senator Metzenbaum and Congresswoman Oakar. I unfortunately or fortunately, whichever the case might be, my wife has Alzheimer's and we detected it about 3 years ago and it was only due to a fall that she had, and we took her into a hospital and she was there for about a week and it was determined that she had Alzheimer's.

I was not satisfied with the answers that I had gotten, so I had taken her to the clinic to confirm it, getting a second opinion and, of course, it was confirmed. Over the past 3 years, of course, she has regressed somewhat.

She at one time had spent time—she was a housewife and we have three children. Two live outside the city or the State of Ohio and one lives here, fortunately. As a housewife, she also spent time doing volunteer work at the hospital and, of course, she spent time at Menorah Park. Due to this, of course, this has changed our whole lives somewhat.

I take care of her. I do have help. They come in twice a week. I now have to take her in to Menorah Park Day Care Center, which I found to be one of the better day-care centers in the area and she seems to enjoy that.

The main problem, of course, is she cannot function any more like she used to. What I try to do is help her as much as I can. Where she used to do all the household bills and take care of that type of thing, I try to give her the sense of responsibility or a sense of being. I still have her sign checks. That she can do. She can sign her name. I give her little things like that to make her aware of a sense of being.

Financially, this has been a problem not only for myself but for many others, as you know. I may be a little more fortunate then some others. I have since had to retire due to this. But in reviewing my costs, which now entail some $1,000 a month, which is $12,000 a year, and people that have an income of $25,000 or $30,000 a year and have to subject them to that type of cost or a nursing home, which can run as much as $25,000 to $30,000 a year, which leaves the individual or the care giver with nothing, is poverty. And if he has not done anything over the years to protect himself in future years, it is devastating. As a general rule, most people try to build their so-called nest egg for retirement and as you hope to retire and enjoy life in your later years, it becomes under this type of situation hazardous. Whatever you try to gain or whatever you try to do goes down the drain.

I know eventually, I have resolved myself, eventually it may get to the point where we may have to put her in a nursing home.

Senator METZENBAUM. Could you afford to do that?

Mr. CHOLFIN. It would be a hardship. One of the things that I have concerned myself with and one thing that should be, as some stated here, they do get Medicaid or Medicare, it does not assist nor any insurance assist. Another area where you cannot get help on is your tax, your income tax deduction, applying it as a medical expense because it is custodial expense and IRS does not look at it that way.

Ms. OAKAR. Could I just ask you, how old was your wife when she acquired this disease?

Mr. CHOLFIN. Sixty-three.

Ms. OAKAR. So many people think that it is just an old person's disease, but——

Mr. CHOLFIN. No; it is not.

Ms. OAKAR [continuing]. A lot of younger old people acquire the disease.

Senator METZENBAUM. I might tell you, Mr. Cholfin, that S. 2222—it is no longer that bill, because Congress, once it adjourns, we start up again—it is a bill that I introduced in January 1984, to provide a deduction from gross income for individual taxpayers who maintain a household which includes a dependent of the taxpayer who suffers from Alzheimer's disease, in these days of budget cutting emphasis it is certainly difficult to move this kind of legislation, and it would provide for a deduction for individuals for home care expenses for dependents with Alzheimer's disease, I think we still have a chance, in spite of that.

Mr. CHOLFIN. That alone would give at least some assistance.

Senator METZENBAUM. Of course. Thank you very much.

Mr. CHOLFIN. Thank you for letting me appear.

Senator METZENBAUM. Ms. Ellis.

Ms. ELLIS. I would like to express my sincere appreciation to Senator Metzenbaum and his staff for inviting me to testify at this important hearing. I am Arlene——

Senator METZENBAUM. Arlene's husband, not only did I play tennis with him, he was just a magnificent athlete. He taught the rest of us how to play. This illness does not affect people who are weak and not in good condition. I would say he was in as good condition as any of my peers. How old is Paul now?

Ms. ELLIS. Sixty-four.

Senator METZENBAUM. Sixty-four.

Ms. ELLIS. I might add that I think because of his athletic abilities and his being able to keep playing tennis for so many years, I think it may have prolonged the devastating effects a little longer.

Senator METZENBAUM. I have another friend of mine who I think participates in the program here on an outpatient basis. I am told that he plays tennis, continues to play tennis, but he cannot find his way to get to the tennis court, but once he gets there he can play. I am sure it is a gradual kind of thing, but it is just another indication of how this illness eats up people, all kinds. Go ahead, Ms. Ellis.

Ms. ELLIS. I am Arlene Ellis. My husband, Paul, is one of the 2½ million persons in the United States who has been afflicted by Alzheimer's disease. I was the first president of the local Cleveland chapter of the Alzheimer's Disease & Related Disorders Association, which is also known as ADRDA. Currently I am serving as the region 5 delegate, representing chapters in Ohio, Kentucky, Indiana, and Tennessee on the board of directors of the National Alzheimer's Disease & Related Disorders Association.

In 1976, when my husband was just 56, slowly building symptoms of changes in intellect, judgmental powers, and routine behavior became too difficult to ignore. One instance when my husband, whose engineering and philosophy background gave him a rich and varied vocabulary, sat at a scrabble game party totally unable to put together even a three-letter word, however, the worse was yet to come.

Soon after I learned that my husband's loss of sharpness had unwittingly caused him to make some catastrophic business decisions. For 2 years we were involved in costly legal suits, and through it all my husband had no conception of our legal dilemma. That is what finally led me to realize that a medical consultation was imperative.

After a series of tests, with a diagnosis of Alzheimer's disease, our family physician told me the diagnosis, with the terse comment of: "Don't expect anything to improve, there is no cure, no help, and from here on in everything will be downhill, to a point where Paul will no longer recognize you and he will decline to an eventual vegetative state."

Being completely devastated with thoughts of the dismal future that awaited us, I clung only to the hope given by a passage I once read that said: "A new door opens for every door that is closed." After a long 2-year period I found a new door opening with the formation of the Alzheimer's Disease & Related Disorders Association.

For these past 5 years I have been extremely active and involved in this organization on the local, regional, and national level. In fact, if I were to estimate the number of hours a week that I spend either visiting my husband in the nursing home or working on ADRDA business, I would say that my involvement with Alzheimer's disease amounts to at least 25 hours a week. This is in addition to the 20- or 30-hour workweek that I put in for my job as a secretary.

It is this kind of commitment in time and effort by family members and professionals all over the country that in just 4 years has helped to building the national organization comprised of 120 chapters and affiliates.

This past month has even seen the development of an international Alzheimer's association. But 8 or 9 years ago when I first learned of my husband's affliction, no organizations like these existed. And even worse, almost nothing was known medically about the disease at all.

In less than 5 years we have made tremendous inroads in public awareness, family support, medical research, and legislation such as Federal support for the establishment of 10 research centers and the availability of respite care, day care and in-home health services.

One of the most important medical and public awareness advances that has changed common conceptions held for decades is that senile dementia is a disease, with Alzheimer's being one form it takes. Alzheimer's symptoms are not the results of the natural aging process but are caused by an unrelenting degenerative illness.

All of the work of our organization is directed toward discovering what can be done for families as well as patients who suffer from this horrible malady that leaves only a loved one's outer shell intact. These past 4 years have indeed been groundbreaking, however, at the same time that progress has been relatively quick in some areas, like educating the public and promoting research, it has been painstakingly slow in others, particularly in getting both government and private medical insurance to cover the medical costs for caring for Alzheimer's patients.

Researchers discover more and more about the pathological nature of Alzheimer's disease, and yet insurance regulations continue to categorize it as a custodial-care-only condition. At the present time, Medicare and private insurance carriers will pay for the services of an R.N. or L.P.N. for other chronically ill patients, but they refuse to do so for Alzheimer's patients, even though many doctors have noted that AD patients need highly trained attendants who understand their very special needs, thus those of us whose loved ones are afflicted have nowhere to turn for help for the financial burden that caring for an Alzheimer's patient entails.

My own personal experience reveals what it feels like to be up against the wall of Medicare refusal. In April and again in May 1983, when I sought medical coverage for private hospital care prescribed for my husband by his physician, I was flatly turned down by Medicare. My physician's letters stated the medical necessity for 24-hour supervision in no uncertain terms. He wrote that since my husband was dangerously dehydrated from pneumonia, IV's were to be administered. However, my husband was constantly hyper and agitated due to Alzheimer's disease and there was no doubt that his uncontrolled thrashings would disconnect the life-supporting tubes.

To complicate matters, any medication given to tranquillize him would have endangered his respiratory functions and his blood pressure; 24-hour supervision then was the only plausible alternative; however, both Medicare and Blue Cross responded with the explanation that the level of care required by my husband was primarily custodial in nature and therefore not within their jurisdiction.

As I see it, however, in this situation the effects of Alzheimer's disease were no less life-threatening than those of cancer in a constant care situation. Proper care of an Alzheimer's patient where the disease can lead to a patient easily jeopardizing his or her own life, if not handled correctly, is not a comfort or cosmetic issue but is medically grounded.

For 16 days and nights of required supervision, the cost of care for my husband was $3,553. I was fortunate to be able to pay at that time, but my concern is for the families who absolutely cannot afford to pay charges such as this.

I implore legislators to give consideration to helping the thousands of struggling, unfortunate families that need financial assistance in meeting the necessities of providing proper supervisional care for loved ones suffering from the ruthless violence of Alzheimer's disease.

I thank you again for having afforded me the opportunity of relating some facts regarding a subject that has been monopolizing my thoughts for close to a decade now.

Senator **Metzenbaum**. Thank you.

Ms. **Oakar**. Ms. Ellis, I just wanted to say that personally I think the law was on your side in getting reimbursed. I do not consider myself an expert, but I think that the intermediate insurer made that decision as a judgment call and I think myself that the law was on your side for coverage.

Ms. **Ellis**. It is a matter of even not knowing who to go to.

Ms. **Oakar**. Well, sometimes what happens is we legislate, as the Senator can tell you, and we spell out the law and then they issue regulations or they have these intermediators and it is—the only other thing I wanted to say was your organization is just dynamite and you really are right, that without your lobbying, and persistence, and so on, you would not see the funding—which is extradinarily minimal—that there already is for support services and the demonstration projects you mentioned, but all the funding for Alzheimer's diease is 0.5 percent, which is about 0.5 percent of the cost overrun of one helicopter project, so in terms of priorities it is way out there. But your group is great and you are to be commended for being so active.

Senator **Metzenbaum**. Before you leave, I just want to say that the television stations in this area, particularly 3 and 8, who I think are with us today, have been very, very supportive, have spent a tremendous amount of time. Both of these women who are here today have devoted themselves to investigation, to pursue the facts, and I must be frank in saying to you that we all know the impact of television in bringing a sense of awareness to people and we appreciate your personal involvement as well as the stations' involvement.

Thank you very, very much.

Ms. **Ellis**. Thank you, Senator.

Senator **Metzenbaum**. Our next panel is Gloria Levine, director of memory imparied program, Menorah Park Home for the Aged; Frances McNew, nurse administrator, L.I.F.E. Center Adult Day Care, Reynoldsburg, OH; and Rachel Billington, administrative director, Alzheimer's Disease & Related Disorders Association, Chicago.

You are all in a little different category. You are sort of pros and I am going to ask you to stick to the 5-minute limitation, if you will, please.

Our first witness is Gloria Levine.

STATEMENTS OF GLORIA LEVINE, DIRECTOR, MEMORY IMPAIRED PROGRAM, MENORAH PARK HOME FOR THE AGED, BEACHWOOD, OH; FRANCES McNEW, NURSE ADMINISTRATOR, L.I.F.E. CENTER ADULT DAY CARE, REYNOLDSBURG, OH; AND RACHEL BILLINGTON, ADMINISTRATIVE DIRECTOR, ALZHEIMER'S DISEASE & RELATED DISORDERS ASSOCIATION, CHICAGO, IL

Ms. **Levine**. I would like to thank you, Senator Metzenbaum, for allowing me to testify today.

Senator **Metzenbaum**. We are happy to have you.

Ms. **Levine**. I am a registered nurse by profession. I have been working in the adult day care area for the past 9 years and for the past 3 years has been rather exclusively involved with people who are suffering from Alzheimer's or related disorders of dementia.

For the past year and a half I have been working in a program for memory-impaired people at Menorah Park and in our day-care center we serve 120 adults a week, 45 of which suffer from Alzheimer's disease in various stages.

Over the past year I have worked with 90 people with Alzheimer's disease and their families. Right now there are 20 people that are in our program who come in from 1 to 3 days a week. We provide stimulation for these people, using skills of the past. Hopefully by doing this, we can maintain their level of function for as long as possible. We provide the most needed thing for the family, the respite. We have heard families talk about the respite that they need, needing the alternatives. We are an alternative that is community based.

It is a tragedy that there is not more funding for programs like ours, for more experimentation to take place with other day-care centers to do this type of thing. It is a tremendous service.

Our families are absolutely delighted when the family member who has Alzheimer's comes back and is in a good mood, can have something to relate about the happiness they have experienced that day or the family member can see the type of activity we are doing that allows this person to perpetuate life.

These people deserve dignity, they deserve the stimulation that they get. They are human beings. This word that we use, "custodial care," bothers me very much as a professional. It may be unskilled care in terms of not being a lot of medication, a lot of nursing care, but they need skilled care by people who understand the disease, by people who understand the people.

One of the other alternatives in the community would be home care, and I noticed as I listened to family members this morning speak in testimony, they talked about the difficulty of finding qualified people to stay with their loved ones at home. I feel there is a great need for funding to be given to social agencies to train people to understand the disease and to know how to manage these people in their homes.

A lot of families have to have no alternative but nursing homes because they cannot find the right type of person to stay in the home.

Ms. **Oakar**. Can I ask a real quick question, as I know we are under a time restraint?

Senator **Metzenbaum**. Yes.

Ms. **Oakar**. Do you think—I am sort of predisposed to answering my own question, but do you think that we ought to reimburse directly nurses and people who provide home services under Medicare so that there is some coverage—you do not really need the doctors involved in that—would that be a step in the right direction?

Ms. **Levine**. I think reimbursement for home care services would be greatly needed. It does not have to be a nurse to give this type of care. We need people who can act as qualified home care service people. These are people that understand the disease, understand the needs of the person that has Alzheimer's, understands that these people need to be stimulated, that they need to be treated with dignity, that they are people that need to be helped to continue to function at their highest level of which they are possible of doing.

Ms. **Oakar**. That is one of the problems I see with Medicare, that the emphasis for reimbursement is on hospitals and our doctors and nobody else——

Ms. **Levine**. Yes; I think with Alzheimer's disease we need to think of alternative care plans with community support bases. There are many families who do not want to place them in the nursing home because they feel their family member can do better at home with the attention and the love and the care that they will get, and I agree with that and our program has proven that because we see what happens to the members of our program who go into a nursing home within 2 to 3 weeks.

Senator **Metzenbaum**. Tell me this: If an Alzheimer's patient's family were to call you and say we would like somebody to come in about 8 hours a day, can you refer us to anybody, are there people that are in that category? I am not talking about registered nurses.

Ms. **Levine**. There are people but those people cost anywhere from $5 to $8 dollars a day—I mean an hour. I wish it was $5 to $8 a day—$5 to $8 an hour. For many families—perhaps the person has been in day care and then becomes no longer appropriate for day care and the family is not ready to make nursing home placement, $8 an hour can run into a lot of money, and the financial burden that these families are under already—and they are constantly thinking about the fact of what is going to happen if I have to make nursing home placement, I know I will not be able to get reimbursement there, what am I going to do—so a lot of times families will say to me when I give them the alternative of home care after day care is no longer appropriate, how can I do this, financially I cannot do this.

Senator **Metzenbaum**. Do you feel that the people who charge $5 to $8 an hour—and I am not questioning that at all—do you feel that they may be overly trained or that there might be a category of people who would be available at something less than that, $5 or $6 an hour, or do you feel that $5 to $8 an hour is essentially about the minimum you could think of?

Ms. **Levine**. $5 to $8 an hour, people who are charging this are not highly trained. They are not trained at all. That is one of the things that I feel is so important for funding, that agencies, community agencies need to have funds to train people who will be understanding of the disease and of the person and perhaps can be hired out at a sliding scale fee. Maybe they cannot be hired out for less than $5, but if the person cannot afford the $5, perhaps from a community agency rather than a private agency a sliding scale fee could be appropriate.

Senator **Metzenbaum**. Also if we made it deductible?

Ms. **Levine**. Deductible or some reimbursement, I think that is something that we really need to look at.

Senator **Metzenbaum**. Thank you very much.

Ms. **Levine**. Could I just mention one other issue?

Senator **Metzenbaum**. Surely.

Ms. **Levine**. When we were talking about the nursing homes, I feel that there is a very important issue of nursing homes that we need to look at and that is the fact that the nursing home as it exists today is a medical model. There has been experimentation going on in the United States only in three or four different areas where nursing homes have taken a unit and made it a social model unit, such as the type of unit that we run by the day-care program, with a very home environment, individual rooms, staff wearing street clothes, staff having the time to give these people the attention they need to help them maintain their level of functioning, use their skills of the past, live in a family atmosphere.

It has been found that the cost is $39 to $49 a day. OK. Families can afford that if there is no reimbursement. The most important fact is that families and the researchers have found that the people stabilize their level of functioning, the deterioration is not as fast and people who have been taken off the medical model units and have been put on this social unit have actually improved in their behavior, not imposed cognitively and intelligencewise, but have improved in their behavior and they are easier to manage.

And I think if we could have more funding for more experimentation in this, this is something that really needs to be looked at, because with the numbers that we are talking about going into nursing homes due to this disease, I think we have to look at something other than the traditional medical model that is being used in nursing homes today to care for these particular patients.

Thank you for the extra time.

Senator **Metzenbaum**. Thank you very much, Ms. Levine.

Frances McNew, nurse administrator of L.I.F.E. Center Adult Day Care, Reyoldsburg.

Ms. **McNew**. Thank you, Senator Metzenbaum and Congresswoman Oakar. I come from the central part of Ohio and I appreciate the opportunity to share with you some of my problems.

I am the widow of an Alzheimer's victim and 5 years ago my husband was diagnosed and evaluated as having Alzheimer's. We participated in research through Dr. Leopold List in Columbus, OH, at Ohio State University, and had many of the traumas that you have heard earlier today.

In addition to that, I would like to stress that in the early stages of the disease, my husband was driving and totaled a car and had an accident. Luckily, no one was killed. We had a fire involving a cabin that was completely destroyed and he was burned when I was attending a VA hospital here, attending a nursing conference.

At this point in our lives we wondered if we did have a family unit. I had two teenage children and they were unable to cope and I did not realize the stresses that they were going through. Even with psychological counseling, I have just found recently my daughter, who is now 22, has told me that she found her step-dad outdoors semiclothed at the age of 16. This certainly, as I look in retrospect, indicates to me that I was not able to meet the needs of my own family as I was going through this crisis.

We became a part of a family support group in Columbus, OH, and it was through that area that we understood what was ahead of us, and I am not going further into those details. But I did take 10 months off from my professional career to be with him and it was during that time that I will always cherish and appreciate the fact that we could actually keep him at home during that period.

The final decision was to enter a nursing home, treat this as a boarding school and I would bring him home on weekends. I did this until the last month of his life and I would like to say that in my daily visitations to that nursing home, I felt in some way as a professional nurse, I was able to improve the clinical nursing expertise within that center.

I assisted in the feeding, bowel and bladder programming, and also ambulation, and it is unusual to hear that a person was still walking until the last week of their life. We went through several bouts of pneumonia, surgeries, and other problems that go along with death.

I was president of the Columbus chapter for 3 years. I now practice 50 percent in the cognitive disorders clinic in the office of geriatrics at University Hospital. I hear weekly, the hundreds of families that go through the stress, that I have expressed to you at this time.

It was through interest and within our Columbus chapter in looking at long-term alternatives and the family support group that met at Reynoldsburg Methodist Church that we went to our ministerial staff seeking an adult day-care program. We utilized the facilities within that setting and our budget after 1 year has been less probably than one person's full-time professional salary. Through the use of volunteers within the church setting, over 30 volunteers are currently working there and we are growing daily in our activities with the Alzheimer's victim and other frail elderly.

We see that certainly the total health care dollars for Medicare are atrocious, but it would appear that one could get at least three times the money returned through adult day care as compared to 1 day's nursing home costs. I looked 4 years ago for this and could find nothing in Columbus.

Within the past year there have been five new day-care centers set up in the Columbus area and only one of them has gotten outside funding so far, so I know there is interest in demonstration projects such as Passport, the Compass, the Pisces Program that is going on, but I have heard of these things for the last 3 years within the Commission on Aging and the Department on Aging and I have been unable to get those moneys.

I approached private foundations in the Columbus area and got turned down. It was through the efforts of the church setting that we have been underwritten, at least $10,000 last year and this year, and certainly I fully appreciate that and I hope that we will be able to continue to grow in our funding.

We do charge $20 a day. We need transportation for assistance to get people to and from, and certainly even $20 a day is self-defeating to many of the indigent community.

The Passport Program specifies that a person's income should be $277 or less before they are eligible for day care coverage, and you can see that certainly is the marginal person that is encountered with day-to-day programs is usually above that income at this point.

What I see as a need is continuing diagnostic evaluative centers across the country to make sure the person has an appropriate diagnosis. I would like to see continuation of documentation in a systematic manner. We are presently involved in a computerized assessment program through the research that we are doing there. We do not have any outside funding at this time at Ohio State, only through internal contributions and personsal contributions through the development fund.

Again, I would like to see additional moneys for respite care and talk and track community home health agencies. The nursing director indicates she has 5 aides to go into homes and she could use 20 today and the funding is not there.

Throughout our Ohio Association of Day Care Centers, there are currently 43 day-care centers. We need the reallocation for moneys, the title XX moneys are drying up, there have never been any funded for day care in Franklyn County itself. This may be a regional problem, but it is what I am encountering as trying to promote the day-care center.

Senator **Metzenbaum**. Thank you very much, Ms. McNew.

Ms. Billington, you are the administrative director of the Alzheimer's Disease & Related Disorders Association of Chicago, headed up by an old friend of mine, Mr. Stone, and we would be very happy to hear from you at this point.

Ms. **Billington**. Thank you, Senator Metzenbaum. I am here on behalf of the national office of ADRDA, as you said, and to begin with I would like to thank you for the opportunity to be here. I was a lifelong resident until recently of Cleveland. I am very pleased and proud to be here.

The president of our association, Jerome Stone, has asked me to extend his warmest personal regards and he is sorry that he could not be here himself.

Above all, Senator Metzenbaum, each of us in the association—and I represent over 300,000 persons represented by our 120 chapters of family support groups around the country—we wish to thank you for all that you have done to raise the public's level of awareness and understanding of this horrible disease. I particularly appreciate the sensitivity that I am hearing here today and the depth of knowledge. I really am very pleased to take this back to the association to recognize this, that this does exist.

We want to thank you for committing so much of your valuable time and energy toward helping to enact legislation to ease some of the suffering, anxiety, and wants that Alzheimer's disease causes its victims and their families.

Without a doubt, your support has made a difference, with your colleagues in the Senate and throughout the country. Greater resources are now being devoted to funding the cause and treatment of a disease that now affects 2.5 million persons or more, and which threatens to afflict many more in the years ahead. Because of your efforts, those with family and loved ones suffering from this disease have good reason to hope.

The increases in research dollars that you helped guide through Congress for the past 2 years have helped to advance research in so many ways—by attracting bright young minds to this field of study and by breaking down so many of the barriers once thought to be overwhelming.

In the future, we expect progress will continue, in part because of your successful effort to establish 10 specialized Alzheimer's centers around the country. I only point out for the benefit of those who may not already know that last year you alone stood in the well of the Senate Chamber and convinced your colleagues that the Research Centers Program was an idea whose time had come.

This year, of course, you helped call attention to the day-to-day anguish endured by patients and families by seeking new legislation aimed at fulfilling some of the critical service needs of families, including the need for respite care in the form of adult day care, in-home care, and short-term institutional care and the provision of transportation.

We have come a long way, Senator, from the time when a few could even pronounce the name of this disease, let along understand its full implications for the individual and for society. Still, some major issues remain, not the least of which are those having to do with the long-term costs of caring for an Alzheimer's victim.

Incidentally, I would like to take an aside for some statistics. Congresswoman Oakar has mentioned the age ranges, and to our knowledge in the association there are at least 60,000 or more persons between the ages of 40 and 60 who have contracted Alzheimer's disease. We know that the larger number are over age 65, but it also affects in rare cases, to be sure, younger persons. As a matter of fact, one board member's wife contracted this disease at age 27. It is devastating to think about.

Our families want to care for their loved ones at home for as long as possible. Some are able to do so and some are not. In the home caring for an Alzheimer's disease victim can be enormously burdensome and stressful for the immediate care giver, usually a spouse or adult child.

The patient, through his anxiety, frustration, confusion, and anger, becomes more and more difficult to manage, in fact, making the care giving process so difficult that our doctor warns us to look for the potential second victim of Alzheimer's disease, the immediate care giver who frequently succumbs to heart attack or some other stress-related disorder.

It is our belief that cost-containment studies will recognize that in the continuum of care required by the Alzheimer's patient, adult day care, home health care, and short-term institutional care can serve at least in part as economically feasible alternatives and will serve often to delay nursing home care, particularly when cost of care for the potential second victim is factored into consideration. We see this as economically feasible.

I know that you are familiar with the fact that medical care for Alzheimer's patients now costs this Nation well over $30 billion annually. That amount is expected to grow substantially as a larger proportion of our population enters the over-65 age group.

Just imagine the impact this is having on families here in Ohio and throughout the country. As you well know, the long-term costs associated with Alzheimer's disease are not covered by Medicare nor most private insurance plans.

Senator METZENBAUM. Ms. Billington, can I ask you to summarize? I am worried that some of these doctors who are here from out of the city, who have made a special trip, have planes to catch and I do not want to lose them.

Ms. BILLINGTON. Of course, this will be very brief from here on.

Senator METZENBAUM. Thank you.

Ms. BILLINGTON. The sad irony, of course, is that assistance does not become available until the family has exhausted most of its resources. After a spouse has spent down practically to the poverty level, Medicaid will step in and provide some relief. But by then society usually has two victims on its hands—the Alzheimer's patient and the family member who must now depend on government transfer payments in order to survive.

Obviously, the problem is particularly severe when the patient has no family or friends on which to rely.

Senator, we realize that from a fiscal standpoint this may not be the best time to be talking about expanding Medicare coverage, but the fact is that this is a real and growing problem, one that we cannot ignore much longer.

Currently, as you have heard, Medicare puts a heavy lid on the provision of care for the Alzheimer's victim. It gives no consideration to the special needs of the patient and family. We hope and pray for relief and seek an equitable sharing of costs of services needed at all stages of the disease, with the hope that the family caring for the Alzheimer's patient need not be financially devastated by the cost of care.

If I may, we receive hundreds of calls at our national office, and to give you in a capsule one call of this nature: A lovely lady called me from Florida several months ago and said: "Rachel, may I talk with you, I just need to talk this out with somebody," and she told me about finally having to place her husband in a nursing home. They had had a little nest egg, she said they had hoped it would carry them through the end of their days so that they would never be a burden on the children. And she said: "Rachel, he has been in the nursing home long enough so that we have spent all of our money, I think he may be dying soon, they tell me that he may, but there will be nothing left, Rachel, what will happen to me?"

Senator METZENBAUM. Thank you very much.

We are going to take about 3 minutes, that is all, just for a little break and we will be back in 3 minutes and then move on.

[Short recess.]

Senator METZENBAUM. The hearing will now resume.

This is Dr. Paul Haber, Regional Coordinator for Aging, Veterans' Administration, San Francisco; and Sister Pat Rogers, northeast Ohio regional administrator, Ohio Department of Aging.

We are very pleased that you made the long trip here and we are very happy to have you with us. It is always embarrassing to get a witness to be willing to come, he travels a long distance and then you say do not speak too long, but we are very grateful to you for being with us.

STATEMENTS OF DR. PAUL HABER, REGIONAL COORDINATOR FOR AGING, VETERANS' ADMINISTRATION, SAN FRANCISCO, CA; AND SISTER PAT ROGERS, NORTHEAST OHIO REGIONAL ADMINISTRATOR, OHIO DEPARTMENT OF AGING

Dr. **Haber**. Thank you. I am Paul Haber. I am the Regional Coordinator for Aging of the western region. Prior to that I served as the Assistant Chief Medical Director for Geriatrics and Extended Care in the central office for many years, and it was there that I developed, through the help of others, of course—Dr. James Bazar among them—many of the programs which I think you know stand us in good stead, including the hospital-based home care and the geriatric research centers which are being used increasingly to treat this devastating disease.

Obviously, Mr. Chairman, I want to thank you and congratulate you on this hearing. For those of us who have been interested in Alzheimer's disease, this is not only a welcome forum but a positive step in the right direction and I thank you.

I would like to briefly outline—I have a statement here which I will submit for the record, but in deference to your request that we constrain the time, I will just excerpt it.

Senator **Metzenbaum**. The entire statement will be included in the record.

Dr. **Haber**. Thank you, sir.

The VA provides health care to a large number of veterans with dementing illnesses through its medical care programs. In its continuing education programs for VA medical staff as well as in its support of training of health care professionals through its affiliations programs, the VA provides training in the causes and management of dementia to thousands of tranineees annually.

Its investigators perform considerable basic and clinical research into the causes, treatment, and management of the diseases affecting the mentally infirm. In all three areas—and I would like to emphasize that the VA is unique in having three areas of responsiblity, first, patient care; second, education; and third, research—the VA is proud of the accomplishments and recognizes that much more needs to be done.

The VA cooperates with other Federal and private agencies concerned with dementia and in particular we are pround of our various associations with the ADRDA, whose members have eloquently been represented here, and several chapters of the association were founded by families working with VA staff. Two VA physicians, to my knowledge, are members of the association's scientific advisory council and we continue to work with them and need them.

Mr. Chairman, I will not go into the demography of this disease—it is known to you—except to say that by the year 2000 we expect to have as many as 150,000 cases of degenerative dementia or Alzheimer's disease. As with many diseases and disabilities, there is no one best place to treat and care for the patient with dementia. The choice of institutional or noninstitutional care depends upon many factors, such as the prognosis, stage of the disease, the degree of disability, special needs of the patient, and the availability of care providers, et cetera.

One of the reasons that we feel particularly capable in the Veterans' Administration is because we have a panoply of resources, including nursing homes, domiciliaries, residential care, home care, outpatient care, respites, hospices, and now the new adult day-care program. So we have a number of programs at the various stages of this disease.

Senator METZENBAUM. Dr. Haber, what is the policy of the VA with respect to keeping a patient or accepting a patient diagnosed as Alzheimer's nonservice connected, is there a policy position on that? I have seen varying attitudes taken by different VA hospitals.

Dr. HABER. Mr. Chairman, our policy is not to admit or deny patients on the basis of a diagnosis, but rather their eligibility. Now, we recognize that Alzheimer's presents a special problem for us, and many of us are anxious to extend ourselves, but we must recognize in terms of giving treatment to the patient, we must recognize that within our resources we must arrange for a variety of other disease, malignancies, long-term congestive failure, and so on, and to the extent that we favor one disease over another we will be penalizing veterans who are afflicted with other devastating illnesses.

Senator METZENBAUM. What becomes the determinative factor as to admission for Alzheimer's or other diseases?

Dr. HABER. Well, the determining factor is the legal eligibility and the medical severity of the condition, those two determine the——

Senator METZENBAUM. And the legal eligibility is what?

Dr. HABER. Well, it is a series of priorities arrayed for us by the Congress, ordained for us by the Congress of the United States which puts treatment for a service-connected veteran for service-connected disability at the top of the list, and then other veterans with other conditions, service-connected veterans with non-service-connected disabilities, a man who is service connected with heart disease with Alzheimer's would be higher than somebody who was totally nonservice connected. That is arranged for us by Congress.

Within our resources, our hope is to be able to care for as many as we can, and I think the testimony you have already heard is part of our policy, that is to say the Veterans' Administration may not be able to treat in its institutions all who might apply, certainly with the numbers I have given you, but that we recognize the continuing responsibility to work with others.

We have arranged for people from Europe under the Kellogg Foundation to come and talk to us and they said their experience is that 80 percent of these patients—and you have heard this this morning—will continue to be treated at home, that is the preferential arrangement. What we have to do is stand behind the family and that is why we have to join hands with the ADRDA, to give counsel, advice, suggestions, and then in the extreme, when the patient is in the terminal stage, to provide institutional care.

Senator **Metzenbaum**. The VA has the hospital program. Do they also have VA homes——

Dr. **Haber**. Yes, sir.

Senator **Metzenbaum** [continuing]. Where Alzheimer's disease patients could be cared for?

Dr. **Haber**. That is right. We have our nursing homes on the grounds of VA hospitals. We also use community nursing homes and State veterans homes. There is such a place in Ohio at Sandusky, and we pay for the care of veterans who are admitted there. All of these will be increasingly useful for us in the treatment of this increasingly common disease.

Senator **Metzenbaum**. The statistics with respect to veterans who may become afflicted with Alzheimer's disease and those whose ages are rising, of course, are quite overwhelming. I am not going to recite them at the moment but will instruct the gentleman handling the report to include the statistics as part of the record to be printed. Does the VA have any plans to formulate a policy with regards to veterans who contract Alzheimer's?

Dr. **Haber**. Yes, sir.

Senator **Metzenbaum**. I did say prevoulsly that I had been successful in getting an amendment through directing the VA to do just that. I am advised that I was not current on that subject, that that matter was taken out in the conference committee. I will come back with that amendment. I can only believe that it was inappropriately taken out and I am a little bit chagrined at this moment that it was taken out. I do not know whether the VA was behind it, the veterans organizations, or what, but it should not have come out because the people of this country believe that the VA ought to have a specific policy on this subject which to the best of my knowledge it does not have in addressing itself specifically to this.

Dr. **Haber**. This policy, Mr. Chairman, is that we are fostering and encouraging more research. We set up the geriatric research centers, I was instrumental in doing that, and one of their top priorities is research on Alzheimer's disease. I am talking now about basic biochemical research, I am talking about behavioral research, I am talking about drug trial studies like Physotigmine which has been found useful, and health services research, all of which are needed.

In addition to that, we have a strong program in education training of health care professionals and families. And third, we have this array or continuum of services of a clinical nature which are going to be increasingly used for Alzheimer's diseases as they present themselves to us. We do not have the whole answer, obviously, but we have within the resources available to us education, research, and clinical care I think to a very satisfactory level, but obviously we can do more.

Senator **Metzenbaum**. Would you be good enough to advise those who are responsible for policy at the VA that I very strongly feel that there has to be some further zeroing in on this issue and that I would hope that they would be prepared to discuss it in-house at the VA and that immediately upon our reconvening I would like to meet with the VA and those responsible so that I need not get a legislative direction but that the VA would accept the responsibility without that and on a date certain would indicate what that policy is. I do not think it would have to be directed by Congress to do it, but I am asking you to convey that information. I ask you, Joel, to follow up that as well immediately after we reconvene, about January 20, I would like to sit down with the VA people and see what if anything they are prepared to do on this subject.

Dr. **Haber**. I would be pleased to convey the substance and the sentiment of your remarks to my superiors.

Senator **Metzenbaum**. I want to tell you, I very much appreciate your testimony and it is quite obvious that you yourself have a real sensitivity to this subject, a good knowledge of it, and it is reassuring for me to know that somebody such as you is involved in the program and I hope that we can reinforce this relationship to the end of helping create a logical kind of program for the VA to have in place so that across the country the same policy will be in effect. I do not think it is at the moment.

Dr. **Haber**. Thank you, Mr. Chairman.

[The prepared statement of Dr. Haber follows:]

STATEMENT OF

PAUL A. L. HABER, M.D.

COORDINATOR FOR GERIATRICS, REGION VI

VETERANS ADMINISTRATION

Mr. Chairman and members of the Subcommittee on Aging of the Labor and Human Resources Committee. I welcome this opportunity to discuss with your subcommittee several aspects of the Veterans Administration's programs relative to dementia, including Alzheimer's disease. The VA provides health care to a large number of veterans with dementing illnesses through its medical care programs. In its continuing education programs for VA medical staff as well as in its support of training of health care professionals through its affiliations programs, the VA provides training in the causes and management of dementia to thousands of trainees annually. Its investigators perform considerable basic and clinical research into the causes, treatment, and management of the diseases affecting the mentally infirm. In all three areas—patient care, education, and research—the VA cooperates with other Federal and private organizations concerned with dementia. In particular, the VA is proud of its various associations with the Alzheimer's Disease and Related Disorders Association. Several chapters of the association were founded by families working with VA staff, and two of the VA's physicians are members of the association's Scientific Advisory Council.

The VA recognizes that over the next several years the number of veterans with dementia will grow rapidly as a result of the increased number of older veterans. We estimate that the number of newly identified cases of dementia will rise from about 50,000 per year in 1980 to 150,000 per year in 2000. The corresponding figures for the total number of veterans with dementia will increase from about 200,000 to 550,000 over the same period.

As with many diseases and disabilities, there is no one best place to treat and care for a patient with dementia. The choice of institutional or non-institutional care depends upon many factors such as the prognosis, stage of the disease, degree of disability, special needs of the patient, availability of care providers, etc. In regards to Alzheimer's disease, there is no treatment known that will alter the course of the disease. The goal of treatment is to provide support to the patient and family in managing the medical, behavioral, and social problems that arise. It is best for the patient to be maintained at home, in a familiar environment or in the least restrictive environment, as long as possible. Most of the initial support measures therefore take place outside the hospital. Alzheimer's dementia is a progressive disease. As the disease progresses, a point is typically reached when the patient can no longer be maintained at home and needs institutional care.

In FY 1982, the VA provided an estimated 1,128,487 days of hospital care to over 27,600 patients with dementia, the majority of whom had Alzheimer's disease or a similar related disorder. Corresponding figures for VA operated nursing homes are 2,593,000 days of care to over 5,500 patients. By 1990 these figures are expected to double.

The VA policy on eligibility for admission is not based on illness or disability. The admission of Alzheimer's patients to VA medical centers is based on medical need, legal eligibility, available resources, and alternatives to institutional care.

A veteran with Alzheimer's disease whose spouse has died and who has few or no other family members to provide care is likely to be admitted at a relatively early stage of the disease. On the other hand, a veteran who has a spouse and family members who can provide care in the home with medical care provided by outpatient treatment at the VA medical center is likely to be admitted at a relatively later stage of the disease. Whether Alzheimer's patients are admitted immediately or placed on a waiting list will also vary from one medical center to another depending upon the availability of an appropriate bed, either hospital, VA nursing home, or community nursing home.

In the area of direct patient services it is expected that the rapid development of the Geriatric Evaluation Units (GEUs) throughout the VA medical system will improve the accuracy and timeliness of diagnoses and treatment of patients with dementia. Between FY 1982 and FY 1984 the number of Geriatric Evaluation Units has grown from eight to twenty-eight and we are planning to have many more in place by FY 1990.

There are a variety of formal and informal clinical activities relative to dementia being carried out throughout the VA in an effort to improve diagnoses and patient care. Since there is no routine way of reporting these, VA Central Office staff, through the VA Medical District Initiated Planning Process (MEDIPP), are devising a survey which will identify the clinical resources available within and outside the VA that are available and used by VA medical centers in the care of patients with dementia. Of particular interest is the degree to which contemporary procedures for diagnoses of dementia are followed, and the extent to which specialized bed services and day programs for care of patients with dementia exist and are used. Availability of such information, along with the projections of the numbers of veterans who will have dementia, will allow the VA to selectively improve the capacity of the medical centers in each of the 28 districts providing care.

A related question concerns the special space and staffing requirements for patients with dementia in long term care institutions, particularly nursing homes. Clinical judgment is divided on the question of the degree to which patients with dementia should be included with other patients or should be segregated. The VA is developing a modification to the existing prototype for VA operated nursing homes which would provide space for the wandering characteristic of demented patients.

The VA has initiated several educational activities to increase our treatment staff knowledge relative to dementia. In FY 1983 the VA, in cooperation with the Institute of Gerontology of the University of Michigan, arranged for five internationally recognized European experts on Alzheimer's to visit three VA medical centers and VA Central Office. The recommendations of these experts to the VA relative to patient care, research, and training have been organized into a report that will be disseminated throughout the VA in the near future. Accompanying the report will be copies of a special issue of the Danish Medical Bulletin devoted to World Health Organization commissioned articles on dementia, including the texts of the lectures given by the experts during their visit.

The VA is also preparing a program guide on dementia for use by its health care professionals. Materials have been prepared by a group of VA and non-VA experts, and the process of editing and synthesizing the material has begun. In addition, VA staff have participated in the preparation of a number of reports and documents that will influence the teaching of comprehensive care of the demented victim to health care practitioners. Notable among these is the report of the Secretary of Health and Human Services Task Force on Alzheimer's

Disease released in September 1984. Multiple copies of this report have been sent to VAMC librarians and Chiefs of Staff. Also noteworthy is the forthcoming American Medical Association Panel Report on Dementia. This report, targeted toward the general medical practitioner, will do a great deal to assist the general medical practitioner to decide when it is necessary to make referrals for specialized diagnoses, how and when to assist the family seeking institutional care for the patient with Alzheimer's disease, as well as how to treat coincident medical problems. Because of the prestige and wide audience reached by the American Medical Association publication it is expected that this report will provide a strong impetus for improved management of patients with dementia.

A large number of VA conducted continuing education courses for health care personnel are improving diagnosis and management of the patient with dementia. In FY 1983 about 10% of the courses dealt with geriatrics and gerontology. Although only a small number were directly related to Alzheimer's disease, a significant number dealt with critical factors in the so-called reversible dementias, e.g., toxic drug reactions, metabolic disorders and infectious diseases. In addition, the Geriatric Research, Education, and Clinical Centers (GRECCs) have sponsored many courses on the diagnosis and treatment of Alzheimer's disease. One GRECC is developing a number of educational materials to help patients and their families cope more effectively with the management of this disease.

The Veterans Administration has made a sustained commitment to research on dementia. Since 1979 the VA has funded 81 studies on senile dementia of the Alzheimer's type. During FY 1983 alone, the VA funded 69 studies on dementia in general. These studies focused on: diagnosis; behavioral and cognitive changes; anatomical and physiological changes; chemical treatments for cognitive deficits; longitudinal social, environmental, and family variables.

The VA Cooperative Studies Program Evaluation Committee has recently recommended approval to fund a large, controlled, multi-hospital clinical trial on the treatment of Alzheimer's disease with oral physostigmine that is expected to provide the most comprehensive evaluation of this clinical intervention. This cooperative study will involve many VA facilities including, in particular, those that host GRECCs.

In addition to VA supported research, VA researchers competed for and successfully won $507,000 of extramural funding for research on senile demential in FY 1983.

The VA also collaborates with other agencies in planning and carrying out research. One of the five Alzheimer's research centers (Bronx VAMC/Mt. Sinai) announced by the Secretary of Health and Human Services, Margaret Heckler, in October 1984 will be directed by a VA physician. Two of the other centers at San Diego and Boston VA Medical Centers have significant involvement of VA scientists and physicians.

The VA is currently working with the Administration on Aging to develop a demonstration proposal to both develop and evaluate the efficacy of various community based services for patients and families of patients with senile dementia. This is still at an early point in its development.

The VA is represented on Secretary Heckler's Task Force on Alzheimer's Disease and a VA representative is the Co-chairperson on the Federal Interagency Committee on Research on Aging. Through these, and other groups, the VA is able to coordinate its research activities, including those on dementia, with those of other Federal and private agencies.

In conclusion, the VA recognizes and accepts the challenge of providing care to veterans suffering from dementia. We are striving to improve our systems of care within our legislative authority and to support our clinical efforts and those of the private sector through research, training, and collaborative activities with other Federal and private organizations.

This concludes my statement. I would be pleased to answer any questions you have.

Senator METZENBAUM. Sister Pat Rogers.

Sister ROGERS. Senator Metzenbaum, I am here today representing Joyce F. Chapple, of the State department of aging, which is the State unit on aging, and I thank you for allowing me to give testimony from the Ohio Department of Aging today on behalf of the victims of Alzheimer's disease, their families, and care givers. My testimony will include what is being done by the State department of aging and what we perceive as future needs.

Since the task force set up by the Federal Secretary of Health and Human Services in 1983 set forth new policies dealing with the problem of Alzheimer's disease, the Administration on Aging launched a special effort to focus nationwide concern about the serious effects of Alzheimer's disease on its victims, their families, and on rising health care costs relating to this problem. Through this effort, State units on aging and area agencies on aging are urged to voluntarily take leadership in stimulating the growth and development of family support groups to help families cope with problems associated with the disease.

On October 15 of this year, Joyce F. Chapple, our director of the Ohio Department of Aging, directed a special appeal to the 12 area agencies on aging in Ohio to work with the local chapters of Alzheimer's Disease and Related Disorders Association [ADRDA] to develop support groups.

The ODA also instructed those in the aging network to familiarize themselves with the devastating effects of this disease and the burden placed upon the primary care givers. Our resource library makes available to the area agencies on aging for this information a four-volume work, and this comprises "Alzheimer Disease Handbook," a "State and Area Agency Instructional Guide," the third volume is "Alzheimer's Family Support Groups: A Manual for Group Facilitators," and lastly, the last volume comprises "Working with Families of Dementia Victims: A Treatment Manual."

The ODA also, in cooperation with the local ADRDA chapters, is planning to provide statewide training to familiarize providers under the Older Americans Act with information concerning the disease and how the aging network can begin to look at its planning process. The aging network must begin to take this population into consideration, both the eligible victim and the care giver.

To advance the care of the victim of Alzheimer's disease and to provide assistance to relieve the primary care givers, many facets of service delivery are necessary. I have compiled a synopsis of needs and I have used for my resources Dr. Leopold List of OSU who has been mentioned previously and Anna Marie Molia, who is the Ohio director of ADRDA who resides in our Martin Jannas Center down in Columbus. This is the synopsis of needs which the Ohio Department of Aging feels should be brought to the attention of the Senate and the Congress.

First of all, respite care, both institutions and day-care centers; second, funding for the above services; transportation to day-care centers and doctors; handicapped facilities for public transportation; more evaluation centers; more day-care centers; music and/or reminiscence therapy; cost evaluation for insurance benefits—and a little explanation of that is there is a limited amount of credit for Alzheimer's patients due to classification as phychiatric patient, instead of neurological patient, which they are; 50 percent of insurance credit is wiped out immediately if the patients are classified as psychiatric—lastly, more funding is needed for in-service, for education of the public, and more resource people are needed to speak out about the problems of Alzheimer's disease.

Alzheimer's disease is a progressive, irreversible brain disease for which there is currently no known cause nor cure. It is one of the most common forms of senile dementia and its incidence is highly correlated with advanced age. It affects approximately 5 to 6 percent of all older persons over the age of 65 and the incidence increases to 15 to 20 percent in persons age 85 and over.

In the State of Ohio, by the year 2030, one in every five Ohioans will be over 65. This statistic points up the dramatic need for research, planning, and action regarding Alzheimer's disease. The collaboration of the Federal Government, the State government, and all components of the aging network is needed.

From the foregoing, you can see that as far as the State department of aging is concerned, we have a long way to go, just as people in the private sector have a long way to go to look at the problems of Alzheimer's disease and what it does to its victims, its care givers and we greatly need the help of the Federal Government in order to do this.

Thank you very much for taking your time today to hear testimony regarding this important problem.

Senator **Metzenbaum**. Thank you very much. It is reasuring to know that someone as sensitive and caring and concerned as you has responsibility in government in this area and it pleases me to know that you are there. Maybe we will not get all the problems solved, but I know you will be trying. I thank you.

Sister **Rogers**. Thank you. In our tiny, little northeast Ohio office we have only four full-time people and I have assigned one of those persons to become more fully informed about Alzheimer's disease and he is on the speakers bureau now, so we know that we have a long way to go in addressing the problem but we are trying to do it.

Senator **Metzenbaum**. Thank you very much.

Our next panel will begin in just a minute, but, Evelyn, I would like to call you back for just one second. There is one question that has been on my mind and I have not had an answer and I am just asking you, since I know you, to address yourself to this, I have a feeling that your involvement with the organization, you can speak for all. Does the patient, does the individual realize what is happening to him or her?

Ms. **Bonder**. I think initially they do. I know that my husband was frightened on many occasions, really panicked because he kept describing it as being unable to make the connection. He knew what he wanted to say apparently, but just could not get the connections made and, of course, that seems to fulfill the description of the doctors and scientists that the neurotransmitters are not working properly.

Senator **Metzenbaum**. The doctors never said to him, "You have an illness called Alzheimer's"?

Ms. **Bonder**. Yes; they did.

Senator **Metzenbaum**. They did.

Ms. **Bonder**. But he did not know what it meant at the time.

Senator **Metzenbaum**. I see.

Ms. **Bonder**. And he was pleased to have some kind of a diagnosis, some kind of a reason that he could fall back on for what was happening to him.

Senator **Metzenbaum**. So the doctors generally do advise the patients of the illness?

Ms. **Bonder**. I am not sure that all of them do. When the term was used to us, neither one of us knew what it meant, so that the diagnosis had no special meaning to us then.

Senator **Metzenbaum**. And this was how many years ago?

Ms. **Bonder**. This was back in 1980.

Senator **Metzenbaum**. Four years ago.

Ms. **Bonder**. Four years ago and I had not heard of the term.

Senator **Metzenbaum**. And you both are very well educated and you did not know what it meant?

Ms. **Bonder**. That is right.

Senator **Metzenbaum**. Thank you very much.

Our last panel is Dr. Joseph Foley, professor of neurology, school of medicine, Case Western Reserve University, Cleveland, OH; Dr. David Roberts, Dartmouth-Hitchcock Medical Center, Hanover, NH; and Dr. Zhavan Khachaturian, Chief of Physiology of Aging Branch, National Institutes of Health, Bethesda, MD.

I am very, very pleased that all of them are here and two of them are from out of the city and Dr. Roberts has been involved in that study at Dartmouth-Hitchcock which has received so much attention. I think there has been a caveat, however, which he will probably address himself to, and that is that although they think that there is some breakthrough, that the case should not be overstated that we are on the road to a cure or a solution, but we will get to that in a minute.

Dr. Joseph Foley—I am taking these just as they are listed here—professor of neurology at Case Western Reserve, we are happy to have you with us.

STATEMENTS OF DR. JOSEPH FOLEY, PROFESSOR OF NEUROLOGY, SCHOOL OF MEDICINE, CASE WESTERN RESERVE UNIVERSITY, CLEVELAND, OH; DR. DAVID ROBERTS, DARTMOUTH-HITCHCOCK MEDICAL CENTER, HANOVER, NH; AND DR. ZHAVAN KHACHATURIAN, CHIEF OF PHYSIOLOGY OF AGING BRANCH, NATIONAL INSTITUTES OF HEALTH, BETHESDA, MD

Dr. FOLEY. Thank you, Senator Metzenbaum, for listening to us and for giving us this opportunity to state our opinions. I would like first of all to state my qualifications, in that I am a neurologist whose career has been devoted for the most part to those behavioral changes which are the consequence of structural and physiological disorder of the brain.

Second, I have been a past president of both the American Neurological Association and the American Academy of Neurology. For some years, in reparation for unidentified past sins, I was the chairman of the National Committee for Research in Nervous and Communicative Disorders, with the responsibility of presenting our case to the Congress.

My major present advantages in the field are gray hair and a loud mouth, a willingness to talk to anyone who will listen——

Senator METZENBAUM. I know that that is helpful. [Laughter.]

Dr. FOLEY [continuing]. A willingness to talk to anyone who will listen and the opportunity for exhibitionism without which the professional class would perish. [Laughter.]

Alzheimer's disease is getting near to the top of the list in terms of public health problems. It probably causes more human misery than all of the nonalcoholic drug dependencies put together. It is a far more formidable problem in the older age groups than is cancer or heart disease. When a single individual is afflicted, there is a radiation effect extending not only through the involved family but into the community of caretakers and the concerned health network.

The cause is unknown, there is no cure, and whenever this is so there will be the recurring cruelty of premature dissemination of unproved methods of treatment.

Although the American physician knows much more about the disease than he did a few years ago, many patients are not receiving benefits of what knowledge is available about the care of patients with the disease. There are many misconceptions, not only on the part of physicians but on the part of other health professionals and health care providers. The magnitude of the problem is such that it is overwhelming the financial researces of the concerned public and private agencies.

Research into the problems of Alzheimer's disease at this point needs to be of two general sorts: There must be a research concerned with cause and there must be a research concerned with effects. There is a danger in throwing all of the talent and the money—and the former is scarcer than the latter—into a search for cause and cure when the number of ideas may not be that great.

Promising present research into cause and cure looks to the location and the nature of the morbid anatomical changes which characterize or are specific for the disease process. This can be done only on human material; there is no animal model. And I think, Senator, you should be proud of people of your State or at least this particular area of your State who have been so cooperative in aiding us to get the autopsy material and to get it on time that allows our investigators to do their work. And I have here, which I may present to you, some of the studies from our university hospitals that have been built largely upon the kind of materials which has been acquired by autopsy.

The other promising approach concerns an increased knowledge of the manner in which the neurotransmitters and peptides of the nervous system become disordered. It must be understood that this kind of research is going to have to be not only at the level of patients with Alzheimer's disease but also at the level of fundamental neurobiology, since we know only some of the neurotransmitters and the neuropeptides which probably are concerned in this process.

The sober neurobiologist who looks objectively at what is happening in the laboratories must admit that not enough is known at this point to make a cure or preventative likely in the immediate future. This does not mean the work must not go on; rather, indeed, it means the work must be expanded and hastened, but again the realist must admit no major breakthrough has been accomplished.

There is a tendency in the face of an incurable disease to go to extraordinary measures even when they have not been sufficiently grounded. Eleanor Roosevelt ardently announced very often that it is better to light a candle than curse the darkness, but in science, and especially in scientific medicine very often, we have to remember the motto in the fireworks factory, it is better to curse the darkness than light the wrong candle. [Laughter.]

Research into the effects of the disease must be accomplished in order to allow a more rational approach to the symptoms and signs of the disorder. Such research might be expected to tell us more about the physical and mental consequences of Alzheimer's disease, might allow us to make some kind of predictions, might allow us to understand better what treatments can be applied in the absence of the cure.

We do not know enough about the natural history of the disease. We need methods of more accurate diagnosis in order to allow us to know what we are dealing with in life. There is no way we can diagnose the case prior to death. We need to be able to make some kinds of predictions about what the future will bring in individual cases. We need to know what medications can be used effectively and without aggravation of the underlying problem.

Nor should such research be only biomedical. Gloria Levine has dramatically told you the kind of thing that social research is concerned with. Research needs to be conducted into the social consequences of Alzheimer's disease insofar as it affects family and other caretakers.

We need further information about the economics of the problem. It is badly misunderstood at this point. Many misconceptions are out there in the community. The whole idea, for example, that in the long run it is cheaper to keep a patient at home than in a nursing home seems to dominate many economic approaches to this. The blunt fact of the matter is that if the patient is being properly cared for at home, then the likelihood is that it is going to be just as expensive as using a nursing home.

If I may digress, I should like to say that I dislike the expression "put into a nursing home," I prefer the expression "using a nursing home."

I would point out that little is known about how to care for patients of this sort either in the home or institutions. Further research in this field must be undertaken.

Why do I make this differentiation between cause and cure or between cause and effect? Let me tell you about a couple of diseases that in my time I have known well. When I was a lad of 30-plus, I still took care of polio, examining in 1949 personally over 600 cases of paralytic polio. I still took care of neurosyphilis, which was a major contributor to the State hospitals in our country. I still took care of the ghastly effects of Koshevnikoff's dementia in our bad alcoholics.

We no longer have polio. We no longer, for all practical purposes, have neurosyphilis, and for all practical purposes largely, Senator, through the influence of Professor Victor based at Cleveland Metropolitan General Hospital here, we for all practical purposes no longer have Koshevnikoff's disease in the alcoholic as a major cause of admission to long-term mental care facilities.

Biological research obviously must go on, and when the time is ripe therapeutic trials must be initiated. The example of multiple sclerosis haunts any neurologist who is concerned with how to approach a research in any field.

We have been assuring the public now for the 35 years I have been involved with it that there will soon be a cause discovered and a cure and preventative found for multiple sclerosis—and please, God, may it be so soon—but we do not have it yet and we do not see anything on the immediate horizon. This is why I plead for research on the effects of the disease as well, because at this stage in our development we cannot say whether 35 years from now we will be in the situation of polio and neurosyphilis or in the situation of multiple sclerosis as we stay today.

We must be prepared for the long haul with Alzheimer's disease by understanding the effects as well as the cause of the process, and by an understanding of these effects we will greatly enhance the understanding of these effects by the addition of appropriate research in fields such as nursing, social work, economics, and indeed ethics.

Thank you, sir.

Senator **Metzenbaum**. Thank you, Dr. Foley.

Dr. Foley, because you do have the gray hair, you have been around the longest so I can ask you this question. Why is it that Alzheimer's has become such a well-known diagnosed illness? The intelligent lady and her intelligent husband, well educated, never heard of the term 4 years ago. Is Alzheimer's new or is it just that it was not being diagnosed?

Dr. **Foley**. No; it is not new. It has been around for a long time. There was a gross misunderstanding on the part of our well advanced American medical profession about it. There are very few even good doctors who recognized that the major cause of mental change in advanced life was in fact a disease. There are still some n'er-do-wells who cling to the idea that the mental changes of advanced age are the consequences of simple aging.

We have a large educational problem to do with the doctors, not only with the lay people. The disease has been around a long time. Back when I was a boy in medical school, the people I dealt with, the neurologists and the psychiatrists, were well aware of this, but it takes a long time.

Now, the reason why it came into sudden prominence is that it became a public health problem. As the population grew older, as the population grew more conspicuously urban, it became clearer that this was a public health problem of enormous magnitude. We find also certain social changes. We find that we have fewer families who are in positions able to take care of these patients at all.

So the urgency, the pressure came, and then finally I think the thing that did it was the noble work of the Alzheimer's Disease & Related Disorders Association. This has been, along with the Multiple Sclerosis Society, one of the very, very best of the voluntary health agencies who have gone out and done their duty to inform the professional and the laity about what was going on, and I think they should accept a large part of the credit for changing the knowledge.

Incidentally, in regard to a question you asked Evelyn Bonder, we sometimes do tell patients they have Alzheimer's disease and we tell them right at the start. In our center, we call the patient and the family and we have to make the clinical judgment about this. Some patients cannot take it, but if they can at all we call the patient and the family in for a full discussion of how we arrived at the conclusion that they have a given disease and then we allow the family to ask any kind of question they want and then we try to map out a care system for them and hook them into the very generous and abundant social network for the aged that exists in this community. This community has a social network better than exists in the rest of the United States, far better, partly through the longstanding Benjamin Monroe Institute and partly because I think this a very, very good medical town, and I have been in many others.

Senator **Metzenbaum**. Can you give us in simple layman's terms the manner in which you make a diagnosis of Alzheimer's as distinguished from senile dementia or something like that?

Dr. **Foley**. Well, senile dementia is in my thinking a generic term under which Alzheimer's disease is subsumed. Alzheimer's disease is the commonest cause of dementias that occur in the senium and that I think is what we mean or should mean by senile dementia. There are other things. There are kinds of high blood pressure going to late life. There is the increasing residuum of patients who have bad heart attacks and suffer diseases of the brain in the course of that, the increasing residuum of people who then are left demented following their heart attacks.

Now, what we do, what we do and what are trying to teach—because much of our role is educational—what we are trying to teach other people to do is to identify the fact that the patient is demented. That means that he has a disease of the brain. The second step in the development is to make absolutely certain—and this is the doctor's first and holiest priority—he has to make absolutely certain that there is nothing going on that might conceivably respond to our medicines or our surgeries, and there are some.

In the screening of the confused and demented older person, probably 20 percent of the patients are going to respond to something that we can do, that is to say they have a preventable disorder. Now, when we have gotten rid of those groups of cases, then we are left with a notion that the patient is demented and has a progressive, degenerative dementing disorder.

Then on the basis of our clinical facts we can sort it out and we say with relative probability that this is Alzheimer's disease, and we explain to the family how we have gone about it, we explain to them the evidence on which we base our conclusion that it is Alzheimer's.

Nobody has mentioned here today, by the way, the genetic predisposition, and that is causing more and more alarm. There is no question I think from all of the data to date that Alzheimer's is a herital familial disorder. It is not as startling a herital familial disorder, say, as is Huntington's disease, but still is herital familial. It has important genetic implications, including genetic relationships to Down's syndrome, for example.

These are considerations that we have to take up with the family. We regard this disease as afflicting not only the patient; we regard this disease as aflicting a community.

Senator **Metzenbaum**. Thank you very much, Dr. Foley. I do not know when I have heard better testimony from a member of the medical profession that I could understand. I feel it was very informative and I am very grateful to you.

Dr. **Foley**. Thank you, Senator.

Senator **Metzenbaum**. Dr. David Roberts, Dartmouth-Hitchcock Medical Center, Hanover, NH.

Dr. **Roberts**. There has recently been considerable interest paid by the news media to a research project at Dartmouth-Hitchcock Medical Center, and given the various inaccuracies and distortions that characterized some of those reports, I am thankful for this opportunity to relate our experience directly.

Senator **Metzenbaum**. And will you tell us your own role at Dartmouth-Hitchcock?

Dr. **Roberts**. I am assistant professor of surgery, section of neurosurgery, and I am part of the cooperative team working on this project that includes neurosurgery, neurology, and psychiatry.

For the past 2 years, primarily the section of neurosurgery in collaboration with psychiatry has been involved in a research project with the continuous direct administration of a drug that mimics the action of a chemical that is know to be efficient in patients with Alzheimer's disease.

There is considerable evidence supporting an hypothesis for the role of a neurotransmitter and a consequent cholinergic system in the brain in cognitive function. Certain drugs will enhance certain cognitive activities like memory, and other drugs that act against that chemical will work against memory or help the memory, as expected.

In addition, research in Alzheimer's patients has shown that a certain enzyme which is responsible for the synthesis of a neurotransmitter, acetylocholine, the enzyme is choline acetyltransferase, this enzyme is deficient in patients with Alzheimer's disease. Furthermore, it has been shown that there is a relationship, a correlation between the degree of that decrease and the degree of neuropathological findings in the brains of patients with Alzheimer's disease.

Finally, it has been shown that there is a degeneration in a portion of the brain consisting of neurons that are part of a cholinergic network of the rest of the brain. It is a dropout of these neurons.

Previous attempts to address the symptoms of Alzheimer's disease by acting on this neurotransmitter either by preventing its degradation or enhancing its synthesis have not been particularly successful. The logic appears sound but the results are inconclusive. And part of the difficulty has been getting enough of that chemical or chemicals to the brain itself. It is very difficult to get certain chemicals into the brain without getting levels in the rest of the body that cause many side effects.

Our approach to this problem is to employ a pump which could continuously administer a drug mimicking acetylcholine and administer it directly into the brain in a way to achieve adequate levels in the brain without levels in the rest of the body that would cause these side effects.

After preliminary animal toxicity studies, we undertook a feasibility study, a safety study in four patients with the approval of the FDA and the approval of the human experimentation committee at our institution. Each patient had biopsy documentation of Alzheimer's disease and then implantation of a pump system consisting of three parts.

First was a pump, roughly the size of a hockey puck, which carries the drug and pumps the drug, and this is placed in the subcutaneous tissue of the abdomen. The second component is a tubing, a small silastic catheter which runs from the abdomen beneath the skin up to the head. The third component is again a silastic catheter which enters the head through the skull into either the ventricular system or the subarachnoid space, spaces intimate to the brain itself.

This pump is now filled with one of two chemicals, one, the active drug, Bethanacol chloride. This is a cholinergic muscarinic agonist, a technical term meaning that it mimics the action of acetylcholine.

The second drug was a placebo, saline, and every 3 weeks the patients had their pumps refilled and either one drug or the other drug was placed in the pump, with the patient not knowing which drug was in the pump.

We reported our preliminary results, our preliminary findings with this study in these four patients as a feasibility study, a safety study. We discussed the rational for the approach, we discussed the technique of implanting a pump system and we discussed the complications that we had seen, and there were complications.

All four of these patients experienced nausea for the first 24 to 36 hours after they had received the drug, and spontaneously this resolved and has not been a problem subsequently.

One of our patients who had a history of symptoms that were perhaps suggested Parkinsonism a while before, developed symptoms similar to Parkinsonism while on the active drug. With cessation of the active drug in the pump and the administration of other medication, these symptoms resolved, and subsequently he is back on active drug in the pump without recurrence of these symptoms.

A second patient developed signs of inflammation within the CSF compartment of the brain, an inflammatory response which did not prove to be infective but the etiology of which was never clear. And again, with removal of the active drug from the pump, this cleared spontaneously and at the present time she remains on active drug without recurrent symptoms.

As I said earlier, our study was a feasibility study and efficacy of treatment was not a goal of this study. We did look at some responses from the patients and there were subjective responses from the patients, from the patients' families that were very encouraging. There was diminished confusion, there was increased initiative, there were improvements in activities of daily living. But these are purely subjective responses of patients and patients' families and in no sense constitute evidence of efficacy of treatment. No claim has been made of efficacy of treatment.

Formal neurological testing, looking specifically at the memory function was looked at in these patients, and no objective evidence of improvement was found, but there were major questions about this technique—in the face of changing drug doses, in the face of certain complications, and specifically with regard to the applicability of certain memory testing in patients with advanced disease where they did not even score on the test prior to the administration of the drug.

All of these methodologic problems made these results inconclusive. We tried to objectify responses, looking at a scale of activities of daily living, measuring how the family performed at home, which after all is far more important than how they perform on a test in a laboratory setting, and there were very encouraging findings with this, but again, methodologic concerns made those results inconclusive.

Our work to date has shown the feasibility of a new approach to Alzheimer's disease. It is directed at improving the symptoms of Alzheimer's disease and is not and will never be a cure for the disease. Much work needs to be done and at the present time there is preparation for a large collaborative study involving a large number of medical centers across the Nation.

Thank you.

Senator METZENBAUM. Thank you very much, Dr. Roberts. You too have given us testimony that is understandable and clear. There were four patients involved in the study?

Dr. ROBERTS. That is correct.

Senator METZENBAUM. And all of the news media reports are related to those four patients, the study, that one particular study?

Dr. ROBERTS. That is correct.

Senator METZENBAUM. And you are now involved in a more broad-based study, as I understand it, which will involve a number of institutions across the country?

Dr. ROBERTS. That is correct.

Senator **Metzenbaum**. And what is the status of that?

Dr. **Roberts**. It is in its planning stages at present. We have about 12 centers that are keenly interested in working with us on this, and each of them is in different stages of preparation, going through their own human experimentation committees, their own discussions between various departments within their centers.

Senator **Metzenbaum**. Are those of you who are involved in the study really quite concerned that the optimism in connection with your studies may indeed be a false kind of optimism and concerned that it has been overstated?

Dr. **Roberts**. This has been a tremendous concern for us. We deliberately let no discussion of this out prior to publication in a peer review journal—published in a journal called Neurosurgery. Yet even prior to this going to press, a national wire service had let out a report on the west coast saying a cure for Alzheimer's disease had been found, a breakthrough, and this was never stated, this was false, and for the past 3 or 4 weeks we have done nothing but try to place this in its proper perspective. This is not a tremendous breakthrough and is certainly not a cure and it has no hope of being a cure, but it is a preliminary report and I do not think it is inappropriate to speak to it. It is a new approach. It warrants scientific investigation, but I think it is terribly cruel to patients with Alzheimer's disease, to their families, and to medical institutions who are trying to do this research to spread this out of context.

Senator **Metzenbaum**. What term would you use other than "cure," and I am not suggesting using "cure," but would you say that this is an indication of an existence of a problem with respect to which you could have some impact?

Dr. **Roberts**. It would be hoped that it might be possible to improve the symptoms. We do not understand. As has been stated, nobody understands the etiology of the process, how the physiology is—it is very poorly understood, but it might be possible by administering a drug to improve some symptoms.

Senator **Metzenbaum**. I do not quite follow you in that respect, Doctor.

Dr. **Roberts**. It might be possible to improve symptoms without addressing the primary degenerative process.

Senator **Metzenbaum**. In improving the symptoms, you are saying that if it is a loss of memory you might be able to regain or to eliminate as much of the loss of memory, that is what you mean by improving the symptoms?

Dr. **Roberts**. Yes; and it is not all certain that memory is what is going to respond.

Senator **Metzenbaum**. No; I use that just as an example.

Dr. **Roberts**. There is an underlying process that we do not understand and this process, independent of a treatment proposal such as this, may continue on and may ultimately be incompatible with survival, but independent of that it might be possible to improve the symptoms that are being caused by this process.

Senator **Metzenbaum**. Thank you very much, Dr. Roberts. Again, I want to thank you for being with us today and I also appreciate the guarded manner in which you and your associates have addressed yourselves to the work that you are doing, and I guess maybe the media overplay is just an indication of so many wanting so much to find some answers.

While mentioning the media, let me just say how pleased I am, as I mentioned before, pleased that the two TV stations had seen fit to give so much of their attention to this subject, and I am particularly pleased that the Plain Dealer has also addressed itself to this subject very well and continues to do so and is here today covering this hearing. I am pleased about that.

Dr. Khachaturian, we are very happy to hear from you. You are Chief of Physiology of the Aging Branch at the National Institutes of Health, Bethesda.

Dr. KHACHATURIAN. Thank you, Senator Metzenbaum, for having me come and testify at this hearing. With your permission, I would like to have the full text of my presentation for the record.

Senator METZENBAUM. It will be included in the record in its entirety.

Dr. KHACHATURIAN. I will present a briefer version here.

Senator METZENBAUM. Thank you.

Dr. FOLEY. May I interrupt?

Senator METZENBAUM. Certainly, Dr. Foley.

Dr. FOLEY. I hope Dr. Khachaturian will tell us about his background in Cleveland, Senator Metzenbaum.

Senator METZENBAUM. Please do.

Dr. FOLEY. An inevitable statement of his qualifications. [Laughter.]

Dr. KHACHATURIAN. I received my education at Case Western Reserve. I live not too far away from here. I am glad to be back home. I consider Cleveland my home.

Senator METZENBAUM. Was Dr. Foley part of the teaching process that you experienced?

Dr. KHACHATURIAN. Yes; indirectly.

Senator Metzenbaum, I speak as a representative of the National Institute on Aging, which is the Federal agency with the prime responsibility for conducting and supporting research on the biomedical and behavioral processes of aging and the disease of aging. Since its inception in 1974, the institute has targeted Alzheimer's disease as one of its most important priorities and challenges.

Since 1977, I have been responsible for developing the Institute's initiative on Alzheimer's disease, and more recently I was responsible for translating congressional intent into producing the guidelines for the center's program. And we are very grateful for our efforts.

What I am going to try to do is in a brief period try to give an overview of what has been accomplished in the last 7- or 8-year period with respect to research accomplishments.

As you have heard today, Alzheimer's disease represents a multiplicity of problems. First, it is a neurological problem, it is a psychiatric problem, it is a geriatric problem, it is a general health care problem, an economic problem, and perhaps a political problem. I am going to only address one aspect of that.

There are many issues to be addressed and investigated. The most important ones are to find out how we can detect this disease, how can we distinguish it from other disease. That is a question of diagnosis. That is an important need.

A second important need is to understand what causes the disease, what is involved in that process. A third important problem for us as a challenge is how to treat this disease; and, finally, how to create institutions to care and provide for the families. These are all challenges.

For this presentation, I am just going to focus in on the accomplishments during the last few years with respect to understanding what causes it. Seven or eight years ago, we started from virtual ignorance in this area, but now we have some incredible accomplishments in the scientific field where we are at the point of proposing some viable hypotheses. The accomplishments have been truly remarkable.

In order to make my presentation in the most concise way, I have brought along a chart, and if I may place it on the board there, it would make the discussion a lot easier. I am sorry it is so small, but it would perhaps make it—the white background might be useful.

What I have tried to do there is try to—in the three circles, the red circle, the yellow circle, and the blue circle, I have tried to identify in a schematic way three very interrelated processes that are essential for the normal functioning of the brain.

The first one has to do with energy, that is blood flow, it supplies glucose, which is the main source of energy to the brain, and oxygen. The second system concerns communication. There are various chemicals that the brain cells use to talk to each other. There are different types of neurotransmitters. One might use the analogy of different languages being spoken in a complex city like Cleveland.

Now, there are not only the short-range communications systems but there are communications systems that have effects on long term, that is, effects that last many, many hours or months, the peptides and hormones do that through neurotransmitters. You have heard about many of them. They do that on a short-range communications system.

Inside the cells there is another kind of communications system, something like an intercom, that are called second messengers.

The third process involves the repair. Brain cells have the capacity to synthesize and produce repairs. The three systems in a very simple-minded way have to work in a coordinated fashion for the normal functioning of the brain. There are various processes that affect these. One is disease, another one is aging, and then there are other issues coming from across the arrows, things like trauma, toxins, viruses, stress, genetic factors which was mentioned, the immune system, hormones, nutrition, and there are many others. I have just indicated a few.

The objective of the scientific community has been to try to untangle these, to understand which factors come first, which come second, and how they are interrelated. The major breakthrough in Alzheimer's disease during the last few years has focused on the communications system. We have learned and we know now quite well that neurotransmitters are a major deficit in a neurotransmitter system. You have heard about acetylcholine.

The neurotransmitter system is one of many. Now research is under way to try to find out if there are more than one type of neurotransmitter systems that are involved. The fact that there is a neurotransmitter system deficit has led to a number of treatment approaches, the assumption being that if one could help the brain cells to continue communicating with each other, then one could, using pharmacologic methods, repair and restore this.

So the treatment approaches that have been used today have used several strategies. One strategy has been to provide the essential ingredients for synthesizing the neurotransmitter. That is the approach using things like lasitine and choline in the diet. Another strategy has been to try to prevent a small amount of the chemical that is released from being degraded, to let it sit around as long as possible. The idea of using physostigmine uses this strategy.

Another strategy that is being used in an experimental way is to encourage the cells to release more of it whenever a cell tries to encourage more of that transmitter. Another strategy relies on changing the sensitivity of those cells that receive the message, and finally another approach has been to use the energy system of the cell.

Now, all these approaches have worked in the early stages of the disease. Unfortunately, in the later stages of the disease these do not work. This finding has led to the speculation that perhaps the reason it works is that cells are still able to perform the minimum function, but what would they do if the cells died? None of the treatments work. This has led to a question of where there is cell death is a major problem in this disease. In fact, our investigators have shown that in specific parts of the brain, specific types of cells die in this disease.

An important question that remains to be asked is why cells die, why specific parts of the brain have these cells that are vulnerable to death. This has opened a whole gamut of challenges for investigators and work is underway. Now, there are various ideas.

One idea is that one of the key markers for the Alzheimer's disease is something called neurofibril tangles. We found out that these things are made up of insoluble proteins and these might interfere with the normal function of the brain, something comparable to a tuft of hair clogging up a sink. It just prevents communication within the cell.

Another finding is that in the Alzheimer's brain, the ability of the cells to use glucose as the main source of energy is diminished. This also could lead to cell death. Another possibility is the onset of slow virus, an infectious agent. This is being investigated. Another possibility is that toxins like aluminum are involved. And finally, more recently it has been shown that head trauma early in someone's life can be an important risk factor. This could lead to problems in the microvascular area of the brain and could interfere with the viability of cells.

These are all various avenues that are being investigated right now.

Senator **Metzenbaum**. You did not mention heredity.

Dr. **Khachaturian**. I will come to that in a moment. I am going to try to wrap up very quickly, saying that there are these opportunities and these areas that are being investigated, and it is possible to tie all these things together because there is a very strong likelihood that the internal workings of the cells are affected.

One important function that cells have is to maintain low levels of calcium inside the cell. All of the things that I have mentioned can affect that functioning. If the regulation of the calcium is disrupted and calcium levels rise within the cell, it could lead to cell death.

Our own intermural scientists have shown that the same process could also occur in the aging myocardium. The point I am trying to make is that now we are at a point where we can tie these various small pieces of findings into telling a cohesive story. The reason we are able to do this is because we have a tremendous backlog of basic information developed through years of basic research, the support of our Congress in providing additional funds for investigators played a role, support we have received from the groups like ADRDA have played an important role in bringing together in a very short time the necessary ingredients; namely, the scientists, the important questions, scientific opportunities, and our hope and expectation is that we will be able to make rapid progress in this area in the coming years.

Thank you, Senator.

[The prepared statement of Dr. Khachaturian follows:]

STATEMENT OF ZHOVAN KHACHATURIAN, PH.D., CHIEF, PHYSIOLOGY OF AGING BRANCH, NATIONAL INSTITUTE ON AGING, NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, this is a statement preented by National Institute on Aging (NIA), the Federal agency with the prime responsibility for conducting and supporting research on the biomedical and behavioral processes of aging and the diseases of aging. Since its inception in 1974, the Institute has targeted Alzheimer disease as one of its most important research priorities and challenges. Within the Public Health Service of the Department of Health and Human Services, the NIA shares an interest and responsibility for this research with its sister Institutes: The National Institute of Neurological and Communicative Disorders and Stroke, The National Institute of Mental Health, and The National Institute of Allergy and Infectious Diseases.

Among the many debilitating disorders of old age, the most frustrating include those that lead to a partial or complete loss in cognitive functioning. Alzheimer disease is one of the most persistent and devastating dementing disorders of old age. It eventually leads to a complete loss of memory and ability to learn. Alzheimer disease presents enormous problems to the families of victims and raises complex social and economic issues for the public. At the same time, the disease offers unusual scientific challenges.

Alzheimer disease is no longer regarded as a natural consequence of aging, as it was only a few years ago. It affects a substantial proportion of the aged, although the exact number of people affected is not known because of the difficulties involved in accurate diagnosis. Many of the families of the Alzheimer patients are now well organized to provide support and share information. The general public is better informed about the disease through our efforts and those of the public media. Secretary Heckler, created an interagency task force on Alzheimer disease chaired by Assistant Secretary Dr. Edward N. Brant, Jr. The task force has prepared and submitted to the Congress a report which outlines a coordinated research strategy for Alzheimer disease.

In the next several pages I will attempt to provide an overview of the magnitude of the problem presented by Alzheimer disease and the remarkable scientific achievements that have already been made.

The number and proportion of elderly in the United States are rapidly increasing and are already having profound influences on American economic, social, and political thinking and behavior. Biomedical research and its applied technologies has made it possible for an increasing number of people to survive until their seventies and eighties. Perhaps the most significant impact will prove to be economic--the costs of needed health care service, availability of clinical resources and biomedical research. Persons 65 and older are at greatest risk for disease and, consequently, have the greatest need for medical services. Many age-related disabilities such as Alzheimer disease tend to be chronic rather than acute, requiring long-term care. Such care is expensive, and the costs are expected to rise due to increased numbers of elderly.

Let's review some of the most dramatic demographic changes of this century:

- The number of people over 65 has risen from 3 million in 1900 to 27 million today and is projected to reach 43 million by 2020—nearly double the current total. At the same time, the proportion of those over 65 has risen from 4.1 percent in 1900 to 11 percent in 1980.
- The greatest increases are among the "old-old," people who are likely to require special care. The segment of the population over age 85 is expected to grow rapidly over the next 40 years, and to reach 5 million by 2020.
- Although nearly 68 percent of older people consider themselves healthy and 90 percent live independently, nearly 86 percent have one or more chronic health conditions or disabilities.

- The elderly account for 15 percent of all visits to physicians, 34 percent of all days spent in short-stay hospitals, 89 percent of all nursing home occupancy, and 29 percent of all money spent on personal health care. In 1984 the total cost of health care service to the elderly is expected to reach $120 billion.

Among the many age-related disabilities, those related to changes in the central nervous system or brain functioning have important implications for both public policy relating to health care services and national priorities for biomedical research. Failure in cognitive functioning is one of the principal indicators for institutionalization of the elderly in long-term care facilities Long-term custodial care in an institutional setting is extremely expensive often impersonal, and may contribute to further deterioration of health.

Approximately 10 percent of the elderly population show clinically significant cognitive deficits. The frequency of intellectual impairment is considerably higher among those living in nursing homes, where an estimated 50 percent or more have some form of mental impairment. A significant number these are now recognized to have Alzheimer disease. In 1982, the annual national expenditure for nursing home care for the aged was approximately $27 billion (Health Care Financing Review, Fall 1983). During the next ten years it is estimated that this expenditure will become a staggering $80 billion in constant dollars. An important issue is that of accurate diagnosis. There are as yet no specific studies identifying the frequency and cause of reversible cognitive impairments in the elderly, but it is estimated that up to 20 percent of persons 65 and over who have been labeled "demented" may have reversible brain disorders that require evaluation and treatment. Misdiagnosis is extremely costly and a tragic waste when it leads to long-term institutionalization. There is clearly an urgent need to continue the quest for scientific knowledge concerning diagnosis and treatment possibilities for dementia and the biological mechanisms both of aging and such dementing disorders as Alzheimer disease.

The dimensions of the health problems posed by age-related changes in the central nervous system are vast. Basic research into the neurobiology of aging as a route to resolving these problems has been demonstrably successful in advancing knowledge of the human brain and providing the first real insights into some of the more baffling neurological disorders. The treatment of Parkinson's disease patients with L-dopa to replace the loss of a vital brain chemical, dopamine, and the discovery of the enkephalins and endorphins--the brain's own "opiate" drugs-- are important examples.

These advances have come about because of a critical combination of talent and technology in neuroscience. It is now possible to obtain a detailed understanding of what happens at the molecular level of a nerve cell as well as a clearer idea of how large clusters of nerve cells and systems operate in elaborating complex human behaviors. Enthusiasm in the field of neuroscience is running high, and researchers are optimistic about the future of brain research. In several areas of investigation, convergent approaches are focusing upon key issues of neurobiology. In order to move toward the fundamental goal of prevention of nervous system disorders, develop effective treatments for those presently afflicted and ensure the rapid transfer of research advance to clinical applications, it is essential to capitalize on this new momentum in neuroscience. Progress in biological science needs good ideas, appropriate biological models--and the necessary technology--the methods and tools to make the observations fruitful. The neurosciences can now command all three of these elements. There has never been a lack of good ideas or experimental models, but only in the last 20 or 30 years have there been significant gains in technological process. These achievements in technology are expected to continue making a substantial difference in the rate of advancement of neuroscientific knowledge.

Although systematic studies of age-related changes in the human brain have a 100-year history, strong interest in this subject is recent. During the last decade a growing community of neuroscientists, spurred partly by the availability of Federal funds for research, has begun to study a broad range of topics in the neurobiology of aging. These range from basic molecular to clinical issues, and from the physical chemistry of membrane transport mechanisms to the neuropsychiatric assessment of the aging brain. Not long ago, little was known about "senility", and Alzheimer disease was considered a hopeless affliction of the aged. Now we know that chemical and physical changes in the brain can account for some of the memory deficits in Alzheimer disease and benign forgetfulness of the aged. The remarkable pace of scientific progress in this area of research increases the likelihood that some forms of dementia may be treatable by pharmacological agents.

Research supported by the U.S. Public Health Service has also made it possible to start formulating a coherent scientific story on the pathogenesis of Alzheimer disease, and to identify a number of exciting scientific opportunities that are ready to be exploited. Of even greater importance is that it is now possible to propose testable hypotheses that can provide a framework for interrelating some of the observations reported by scientists working in this area of research.

During the past few years, it has been clearly established that the hallmark of Alzheimer disease is a serious defect in the cholinergic system. This finding has stimulated considerable scientific activity aimed at identifying the exact nature of this neurochemical defect and finding a pharmacological means of ameliorating the disease. This type of research has been driven by the assumption that the neurochemical deficits in Alzheimer disease result primarily from biochemical abnormalities in the synthesis or release of the neurotransmitter acetylcholine; it is assumed that the affected brain cells would function normally if these biochemical abnormalities could be corrected. Thus, the search for treatment has focused on pharmacological manipulations aimed at: (1) increasing the supply of the substrate necessary for the synthesis of the neurotransmitter, (2) increasing the amount of the neurotransmitter released, (3) prolonging the availability of the neurotransmitter at the synaptic junction by blocking its breakdown, and (4) manipulating the sensitivity of receptors at the postsynaptic membrane.

Despite some promising initial results in treatment of Alzheimer disease with agents such as choline, lecithin, and physostigmine, this effort in cholinergic pharmacology has not produced any consistent or long-lasting treatments for Alzheimer disease. Several theories attempt to explain this lack of success:

1. It is unlikely that Alzheimer disease results from a deficit in a single neurotransmitter system. There is mounting evidence that multiple neurotransmitter systems and neuropeptides are involved.
2. The observed neurochemical changes in Alzheimer disease might be epiphenomena associated with or a consequence of cell death. In Alzheimer disease cell death occurs in specific regions of the brain, particularly in areas richly innervated with cholinergic cells.
3. The neurochemical deficits might be a consequence of other changes within the cell, such as abnormal oxidative or glucose metabolism.

Investigators have yet to determine why brain cells die in Alzheimer disease and whether such cell death can be averted by pharmacological means. There are several working hypotheses concerning the possible mechanisms of cell death. One of the most active areas of study focuses on the chemistry of neurofibrillry tangles. Paired helical filaments make up the neurofibrillary tangles within nerve cells that are the classic pathological markers of Alzheimer disease. It is now known that these filaments are composed of a highly insoluble protein formed by a crosslinking reaction. These insoluble protein masses may form a physical blockage that interferes with axoplasmic transport mechanisms, thus leading to cell death. It is essential that future research focus on the biochemistry of protein crosslinking reactions and on the enzymology of such reactions.

Another important area of study concerns the role of neuromodulators (chemicals that modify the effects of neurotransmitter) and neurotrophic factors affecting the functioning and viability of cells. There is some evidence that the function and viability of the nerve cell might be compromised when there is no chemical feedback or neurotrophic factor from a target cell. The role of neuropeptides such as somatostatin and the mechanisms by which they modulate neuronal activity are not well understood. Whether such neuromodulators also serve as trophic factors is not known. The chemistry of neuromodulators and the neurotrophic factors is an area that needs greater emphasis.

A third area of needed study concerns the biochemistry of metabolism within the cytosol, especially oxidative metabolism and glucose utilization. It is important to have a better understanding of changes in such metabolic pathways associated with aging and disease states.

A fourth cluster of essential studies looks at membrane biophysics and how membrane changes influence transport and homeostasis of essential ions such as calcium. There is some evidence that aging as well as certain diseases causes changes in the transport mechanisms that regulate cytosol-free calcium concentration. We need to learn more about the biophysics of ion channels; pumps, and transport systems associated with cell and organelle membranes.

Finally, we need to know more about such environmental toxins as aluminum and infectious agents such as the slow-acting viruses or virus-like particles that have been associated with cell death in Alzheimer disease. The chemistry of how such agents interfere with cell functioning is still not well understood. Also, we do not know why there appears to be selective vulnerability; the role of genetic factors in such selectivity is an area needing greater study.

All of these results are extremely important because they provide a crucial beginning for piecing together the Alzheimer disease puzzle. It is now possible to formulate testable hypotheses that can provide a common framework for interrelating a number of the discrete results discussed here. For example, in study after study we are seeing the importance of calcium levels within the cell in terms of cell-to-cell communication and even the viability of the cell itself. Time after time, findings in Alzheimer brains point to a disruption in the delicately balanced homeostatic system of transporting calcium across the cell membrane. Such a disruption of the system could be a consequence of exposure to a neurotoxin, such as aluminum; pathogenic agents, involving either genes or infectious agents; other insults; or even aging. Further study should allow us to develop integrated theories of aging and better understand the biological mechanism of diseases such as Alzheimer disease.

In summary, the systematic study of Alzheimer disease began only within the last decade, despite the fact that the disease was first described nearly three-quarters of a century ago. In this brief period of time, our knowledge of this disease has advanced from nearly total ignorance to a level where it is possible to begin testing possible treatments, and formulating viable hypotheses to explain its causes.

The scientific community now has the tools, the knowledge base, and the means to solve the problem of Alzheimer disease within the next decade. This remarkable progress in dementia research has been made because the availability of scientific knowledge, technology, and methods--the bricks and mortar to start building a structure--has been more than equalled by increased interest and enthusiasm in the medical community and among the general public.

The Public Health Service, of which the National Institute on Aging is a part, has supported a significant proportion of basic biomedical research in this country during the last 30 years. A tremendous amount of this work has had direct and indirect bearing on our understanding of the basic mechanism of cell function, including neurons. Using knowledge gained from such areas of science as biochemistry, cellular and molecular biology, bioengineering, physics, genetics, recombinant DNA, and cloning technology, it is now feasible to make rapid progress in understanding the cause or causes of Alzheimer disease as well as other disabling disorders of the aged.

There is no reason to doubt that progress and scientific achievements will be any less spectacular during the next few years as they have been recently, provided we are able and willing to maintain the enthusiasm of the scientific community and provide the necessary resources. The challenges of understanding Alzheimer disease and finding a cure will require the national resolve to maintain the momentum we have begun.

Thank you for this opportunity to speak with you about Alzheimer disease.

Senator METZENBAUM. Thank you.

Dr. Khachaturian, your last statement is encouraging, but I would like to just speak to it for a moment, that your hope, some research, some work has been done, is being done, are there any indications at this moment that progress is indeed being made, that you are arriving at any particular conclusions with respect to any of the subjects about which you spoke this morning?

Dr. KHACHATURIAN. Senator, I am speaking from the perspective of being in a position where I see a lot of projects come across my desk because our organization, the National Institutes of Health, supports the bulk of the research nationally. I started this area in 1977. There was virtually very little being done. We had only a few grants and at scientific meetings maybe one paper was being presented, in the journals there were maybe one or two presentations.

Right now there are an incredible number of scientific meetings and neurological journals that have several articles each issue. Having seen that progression, I am making an interpolation that this field is moving very rapidly.

Senator METZENBAUM. Dr. Khachaturian, let me then share with you a thought and that is if you feel it is moving rapidly and but for the fact that there is a limited supply of money, even though we have been able to fund 10 research centers, I would like to urge upon you that you advise me promptly if you say if we had $50 million or if we had $10 or $200 million, we in the Congress do not know. We respond when somebody presents us with facts. And if you see that in a particular area of endeavor that there is encouraging evidence that it ought to be, that the research ought to be expedited, it ought to be moved more rapidly, but for the lack of funds, I would strongly urge you to convey to me through the appropriate communication that we have that though, because I feel confident that if more is needed—one of the issues that has been raised, and I remember when I as a private citizen was cochairman of the National Citizens Committee for the Conquest of Cancer, and the feeling then was we were just throwing money at the problem and that more money than could actually be wisely spent, nobody wants to do that.

But if we are underfunded and you think that in some particular area with some extra resources that there could be some breakthrough——

Dr. KHACHATURIAN. Senator, my recent statement is organized along the lines of identifying scientific opportunities. As you recognize, I cannot freely speak about the dollar amounts, being a member of the executive branch, it is difficult for me to address that issue, but I can identify scientific opportunities.

Senator METZENBAUM. We will explore that further with you and through the appropriate channels, because I understand the constraints that are imposed upon you as being part of an administration team, the National Institutes of Health team, and that one doctor or one person does not get out ahead of the whole organization. I am aware of that, but we will attempt through the appropriate means of communications to get into that subject further.

Dr. FOLEY. Senator, may I make a comment in regard to this?

Senator METZENBAUM. Surely.

Dr. FOLEY. I think the addition of money is splendid as long as the addition of money does not too seriously constrain the specific approaches to be taken. I think the addition of money for the acquisition of new talent, new minds at this stage in development would be far better used than money for the development of new machines without the proper people to use them.

I would point out also the general unanimity of interest in neurological disorders. For example, the discussion you have heard today about acetylcholine, choline acetylase, that entire system—most of that information comes from work that has been done on myasthenia gravis, in other words, not Alzheimer's disease at all. It is entirely possible that work on Alzheimer's disease may make a huge difference in my myasthenia gravis, it is entirely possible that the current work being done on Huntington's disease may make a huge difference in what we find out to be useful about Alzheimer's disease.

We need more talent in the field of neurobiology and we need ways and means of seducing that talent to come into the battle against human disease.

Senator METZENBAUM. Thank you very much, Dr. Foley.

I want to thank each of the members of this medical panel. I think you testimony has been extremely helpful. I think it is good. I think It is well-directed and your efforts in your own endeavors out in your own fields are appreciated by all of us.

I want to publicly say that this hearing could not have been put together without Joel's help and others from my staff, such as Candy Corn and Lad Anthony, Roz Disbro, and Jennifer Cooper, and to all of you from ADRDA. I am very grateful to all of you for your helpfulness and your support and I feel that we have made considerable headway in this hearing today. It certainly has been very enlightening to this Senator, and I know that Congresswoman Oakar, who had to leave for a 12 o'clock engagement, has indicated that whatever way I move in the Senate she will be very happy to move in the House on the same subject, and I know that I have many of my colleagues who are prepared to pitch in and help.

Thanks to all of you for sharing the morning with us. I think you have contributed much and I hope that maybe we have contributed just a little bit of light on this very difficult and challenging issue. Thank you.

[Whereupon, at 12:55 p.m., the subcommittee was adjourned.]

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